

**THE EXPERIENCE OF SOCIAL SUPPORT AT A CAMP FOR SIBLINGS OF  
CHILDREN WITH CANCER**

A Thesis

by

SAMUEL GEORGE ROBERSON, SR.

Submitted to the Office of Graduate Studies of  
Texas A&M University  
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

August 2008

Major Subject: Recreation, Park and Tourism Sciences

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Approved by:

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Committee Members,	Clifton E. Watts
	Wm. Alex McIntosh
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## **ABSTRACT**

The Experience of Social Support at a Camp for Siblings of  
Children with Cancer. (August 2008)

Samuel George Roberson, Sr., B.S., Weber State University

Chair of Advisory Committee: Dr. Peter A. Witt

Childhood cancer has obvious impacts on the children themselves, but also has impacts on their families and siblings. While studies have been conducted on the impacts of cancer on children and their parents, there has been limited consideration of the impacts of cancer on healthy siblings. Some studies have suggested that siblings of children with cancer are the most emotionally disregarded and distressed of all family members as a result of their sibling having cancer. Exposure to stress has a negative impact on the immune system and places siblings at risk for health problems. Thus, finding mechanisms to ameliorate stress are critical. Early intervention and treatment may serve as protective factors against risky behavior and lead to more normative child development and well-being. One method of improving the psychosocial adjustment of siblings of children with cancer has been through interventions such as camp experiences that include opportunities for campers to experience social support. There is a need to better understand the efficacy of intervention programs designed to reduce stress across a variety of settings. The focus of this study was if campers experience

social support (emotional, informational, and instrumental) at a three and one-half day residential camp, and the elements of camp campers' identified as leading to social support.

Participant observations of camp and semi-structured interviews with selected campers were used to help gain insights concerning the impact of the camp experience on siblings of children with cancer. Coding of responses was undertaken, which led to the identification of themes and subthemes.

Findings provided a narrative description of how campers perceived social support. In addition, social comparison was identified as a critical mechanism for meeting camper's biological, physiological and behavioral needs. Overarching perceptions of campers were that people at camp were nice and staff was instrumental in facilitating universality and a cycle of reciprocity. Implications of this study suggest intentionally designed camps have the ability to impact a broad range of attitudes and behaviors. The study also supports theory of how structures and processes of social relationships work in relation to good health; and can be applied to a camp setting.

## DEDICATION

Ms. Julia Commer was an informal Godmother for me as an adolescent growing up in an impoverished neighborhood, Hunters Point; in San Francisco, CA. She was a guardian for community youth all over the city. She was dedicated to a lifelong labor of service in San Francisco advocating for equitable education opportunities and social justice. She was a community activist; school board watcher; and a community informant for several mayors and politicians. Martin Luther King once said, “The greatest thing that we can do is to do for others.” I was fortunate to have the opportunity to grow up observing Ms. Commer’s love for the welfare of her community. Although unaware as a youth, later, as an adult, I came to appreciate the influence that she had on my life. I have followed her mentoring and have attempted to make a difference in my communities. Ms. Commer, 40 plus years my senior, always told me that I was special; smart; gifted; a good kid; a good teen; a responsible adult; and lastly a good father. Her opinion penetrated deeply into my psyche helped to develop my sense of identity, self-esteem, self-confidence, and self-efficacy. I am thankful that she was an example of how supportive, non-parent adults can give an ounce of love and care and produce a pound of results in the life of a youth. I was honored to have Ms. Commer represent my deceased parents during my wedding ceremony. Therefore, with all due respect to my deceased parents, family, and friends, I dedicate this study’s work on *The Experience of Social Support at a Camp for Siblings of Children with Cancer* to the legacy of Ms. Julia Commer (July 19, 1920 – May 19, 1997).

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Finally, thanks to my loving wife, Traci C. Roberson for her encouragement, patience, and love.



**NOMENCLATURE**

CGD	Camp Grey Dove
ABC	Any Baby Can Family Service Agency
PK	Peaceable Kingdom Retreat for Children, Inc.
CIT	Counselors in training
A&M	Agriculture and Mechanical

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## CHAPTER I

### INTRODUCTION

Childhood cancer is among the leading causes of illness-related death of children in the United States (National Cancer Institute, 2008). Childhood cancer has obvious impacts on the children themselves, but also has impacts on their families and siblings. While studies have been conducted on the impacts of cancer on children and their parents, limited consideration has been given to the impacts of cancer on healthy siblings (Murray, 1999). Williams (1997) has suggested that siblings of chronically ill children are at risk for behavior problems, lower social competence and self-esteem, shyness, somatic complaints, poor peer relations, delinquency, loneliness, isolation, anxiety, depression, anger, excessive worry, and poor or failing school grades. Siblings of children with cancer often find their normative development slowed by the priority given by parents to their ill sibling's treatment and thus siblings may be at risk for delayed maturity and development of socialization skills. Early intervention and treatment may serve as protective factors against risky behavior and lead to more normative child development and well-being.

Martinson et al. (1990) and LaGreca (1992) have suggested that it is the siblings of children with cancer who are the most emotionally disregarded and distressed of all family members as a result of their sibling having cancer.

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This thesis follows the style of the *Journal of Leisure Research*.

People under stress are more susceptible to illness; depression, anxiety, low self-confidence, and dissatisfaction with life then are people not experiencing stress (Martiniuk, 2003). Exposure to stress has a negative impact on the immune system and places siblings at risk for health problems. Thus, finding mechanisms to ameliorate stress are critical.

Despite existing research, there is still a need to better understand the efficacy of intervention programs designed to reduce stress across a variety of settings. In studies that have been conducted, Murray (2001) suggested that a possible method of improving the psychosocial adjustment of siblings of children with cancer was through interventions such as camp experiences that include opportunities for campers to experience social support. As a part of an overall strategy to assist families dealing with cancer, three types of camps are generally offered: family, cancer patient, and sibling. Each of these camps afford opportunities for fun activities, group session time, relaxation, and opportunities to make connections with people experiencing similar circumstances.

House's (1987) research also points to how useful camps can be for siblings of children with cancer as they face the challenges related to family functioning and stress in the wake of this illness. Typically, camps provide recreational opportunities, while camps for siblings of children with cancer might add group process activities that afford opportunities for children to discuss their family circumstances with non-threatening similar others.

Some research efforts have been undertaken to understand how camp attendance impacts feelings of social support, which is thought to play a role in how children cope

with having a sibling diagnosed with cancer (Murray, 2001, Roberts, 1988; Williams, 1997).

Feelings of social support may depend on social comparisons that individuals make while they are at camp. Social comparison theory suggests that as humans, we have an innate drive to evaluate our emotions and abilities (Meltzer, 2003). One mechanism for achieving comparison is to equate one's personal circumstances to those of others as a way to understand and cope with difficult life circumstances. "Upward comparisons" occur when comparisons are made to others who are better off, and "downward comparisons" occur when comparisons are made to others that are less-fortunate. Downward comparisons are often helpful to coping as these often present a case where the situation could be worse (Meltzer, 2003). While the Meltzer's (2003) study demonstrated that through the mechanism of social comparison, campers reported feeling greater similarity to camp peers than non-camp peers, and improved psychosocial outcomes, the study stopped short of identifying what designed or natural factors led campers to their improved perceptions (e.g., social structures and processes naturally occurring within a camp setting). If we can better understand these factors, camps can intentionally plan and design the camp experience for maximum impact. Moreover, if we can better understand camper's perceived social support, then we can better plan the intentionality of interventions to increase these positive perceptions of support.

Social support has been posited in the literature as having the potential for either a main effect or buffering effect in the presence of stress. Some have suggested that social supports are likely to be protective of health only in the presence of stressful



circumstances (Kaplan, Cassel, & Gore, 1977). Social support literature outlines four types of support (House, 1981):

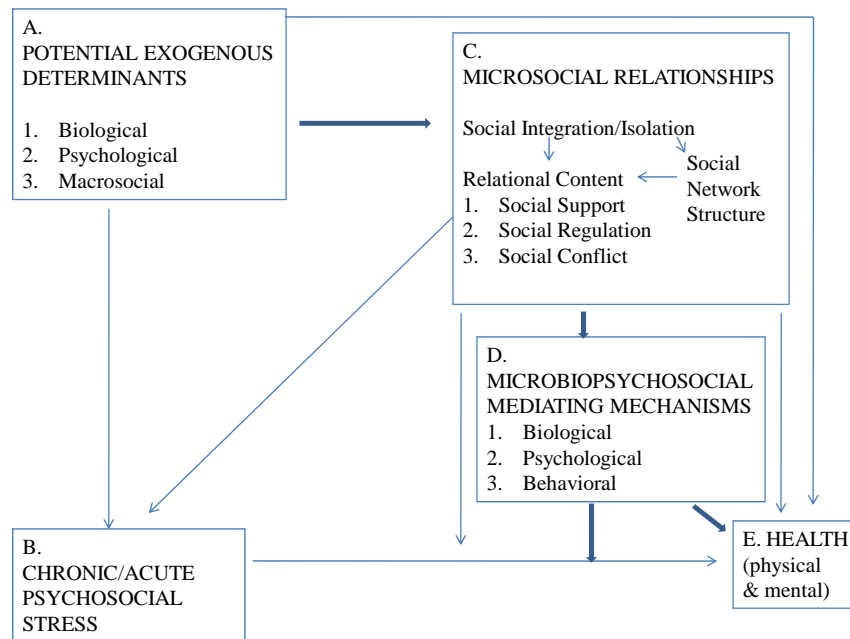
- *Emotional support* is associated with sharing life experiences. It involves the provision of empathy, love, trust and caring.
- *Instrumental support* involves the provision of tangible aid and services that directly assist a person in need. It is provided by close friends, colleagues and neighbors.
- *Informational support* involves the provision of advice, suggestions, and information that a person can use to address problems.
- *Appraisal support* involves the provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison.

A theoretical framework put forth by House, Umberson, and Landis (1988) is helpful in understanding the designed and natural factors leading campers to perceive social support and ultimately improve their well-being. House et al. framework of structures and processes of social relationships to health suggests that biological, physical and behavioral mechanisms interact with the relational content of social support and lead to improved perceptions (Figure 1).

House et al. (1988) also suggests that people have different levels of biological (basic need for attachment), psychological (purposeful social interactions), and

macrosocial (social structures e.g. lower or upper social economic status) health conditions that impact how they respond to stress. These variables are shown in Box A of Figure 1. Psychosocial stress associated with the reality of the potential for death of a child or sibling with cancer can be a difficult for anyone to deal with. Thus, campers come to camp with varied degrees of chronic or acute stress and needs for health adjustment. This variable of psychosocial stress is shown in Box B of Figure 1. For some, arriving at camp can be frightening adventure away from the familiarity of family. The burden of fears and anxieties associated with having a sibling with cancer or the loss of a sibling to cancer can be overwhelming, as evidenced by a young female camper that departed early from camp. The camper's recent lost of a sibling prior to camp was too much for even the supportive environment of camp to overcome.

House et al. suggests that the experience of microsocial relationships can lead to a main effect (meet a basic human need) or buffering effect (enhanced coping ability) that can lead to improved health (psychological or physical).



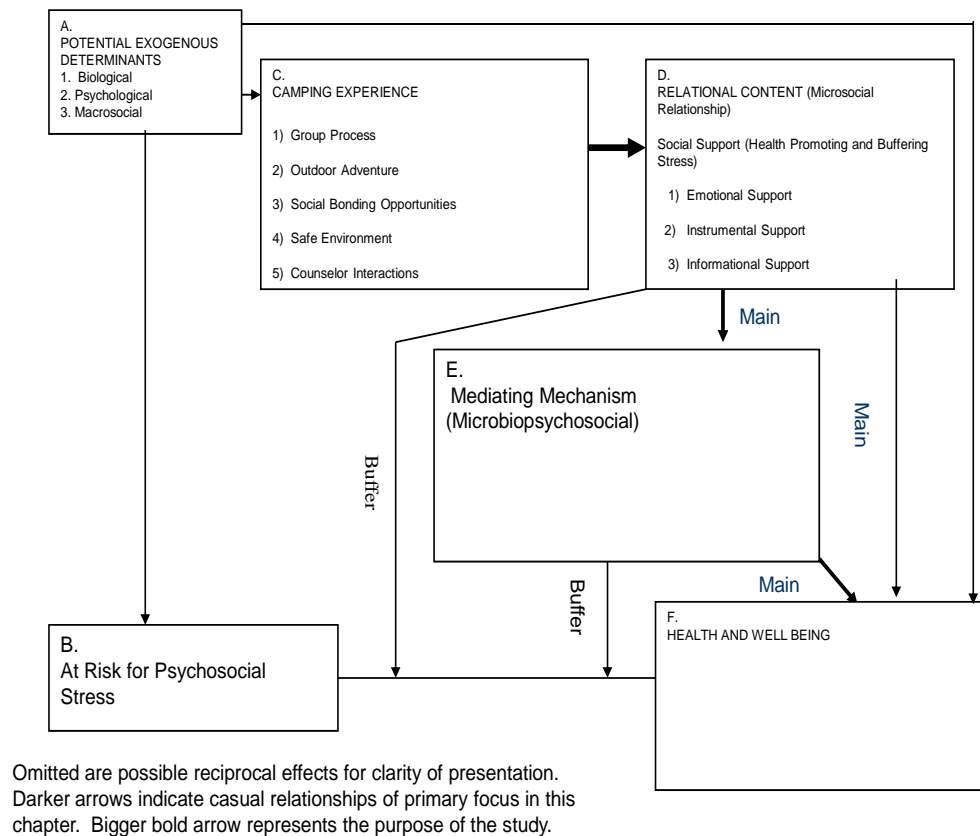
*Figure 1: Framework for Research on Structures and Processes of Social Relationship in Relation to Health (House et al., 1988, p. 303).*

The concepts and a set of potential causal relationships, associated in the literature with perceptions of social support are shown in Box C of Figure 1 representing microsocial relationship. It has been reported in the literature that people with more active relationships, e.g., frequent interactions within their networks, tend to be healthier and live longer as a consequence of having access to social relationships. Access to social relationships can also mean the availability of social resources in times of distress. In House's framework, social integration refers to frequency of relationships and social networks refer to characteristics of those relationship types.

While camp settings can potentially stimulate frequent and multiple types of relationships, the focus of this study was on how campers perceived the camp experience interacts with the relational content of social support (emotional, informational, and instrumental) to lead them to perceived being supported and having enhanced psychosocial adjustments. By inserting the camp experience into the model, social integration (quantity) and social networks (types) microsocial relationships have been replaced by the camp experience. Box C in Figure 2 provides a conceptual modification of House's framework as it applies to camp settings that provided opportunities for microsocial relationships.

The provision of social support may buffer or enhance health and well-being by meeting important human needs for security, social contact, approval, belonging, and affection through the provision of emotional support (House, 1981). However, House et al. (1988) model suggests that a main effect from social support relational content is likely to be mediated through the microbiopsychosocial mechanisms, shown in Box E of Figure 2, in his framework as noted by deep lines drawn.

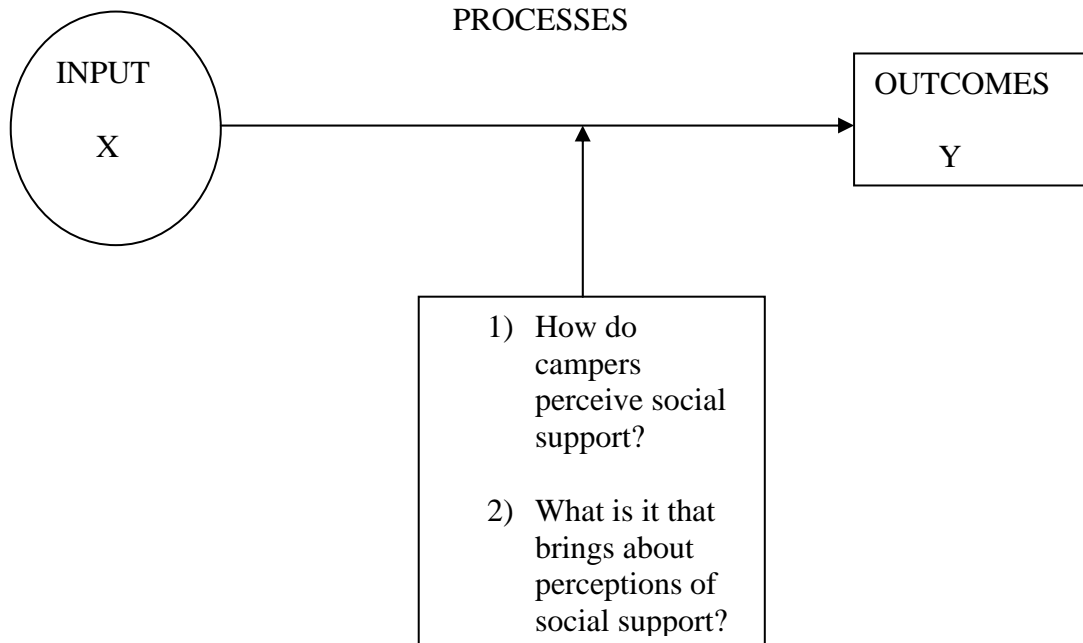
Based on prior research in camp settings, social support appears to provide impacts on camper's feelings of attachment and thus a main effect on their basic human need for belonging. However, camp can also provide a buffering effect, by providing social support for campers experiencing moderate to high levels of stress, but perhaps less impact for campers experiencing little or no stress in their non-camp environments.



*Figure 2.* Adapted Framework for Research on Structures and Processes of Relational Content of Social Relationships in Relation to Health.

House et al., (1988) also suggest a need to understand when, how, and why main and buffering effects occur. For example, through participant's reports and observations of campers, social support occurring at camp appeared to lessen burden or improve emotional well-being. Therefore, in addition to seeking to confirm how social support was perceived by campers, this thesis, guided by House's framework, makes an attempt to elucidate how mechanisms at camp are interacting with the relational processes at camp to increase camper's perceptions of social support.

The current study was designed to explore how campers perceive social support and to understand better the processes or mechanisms occurring at camp that bring about reports of social support. A more practical modified version of House's complex framework was designed with a purpose of helping simplify the conceptualization of the study's purpose, as shown in Figure 3.



*Figure 3: Amended Model Pre-study.*

## **Research Questions**

While studies have demonstrated that social support and social comparison occur at camp, these studies have generally not delineated the characteristics of the camp experience that produce outcomes. Thus, the purpose of this study was to explore camper's reported perceptions of social support while they were at camp by conducting an interpretive analysis of what aspect of the camp experience led campers to feel supported.

To achieve the study's purpose, qualitative data were collected to examine what factors led campers to perceive social support at camp. Semi-structured interviews were conducted with campers and observations were made during camp to help confirm that social support was perceived and to identify the mechanisms through which social support occurred.

The study was conducted at Camp Grey Dove (CGD). CGD is a resident camp program of Any Baby Can, an Austin non-profit agency. CGD is part of an overall agency strategy to provide support services for families of children with special needs. The camp was held at Peaceable Kingdom in Killeen, TX. The camp lasted 4 days and served siblings of children with cancer. There were two camp sessions, one serving children ages 7 to 10 and the other children ages 11 to 14. All campers had siblings who were living or had lived with cancer. Some campers were attending camp for the first time, while others were repeat campers.

It was anticipated that through the mediation mechanism of social comparison, campers would experience increased perceptions of social support at camp and at home.

This experience was influenced by the camp setting providing a safe environment, group process activities, outdoor adventure activities, and opportunities for social bonding among campers and with counselors. While a several of studies have shown that these activities can lead to perceived social support (Meltzer, 2003, Williams, 1997), the current study was designed to understand what specific aspects of the camp experience lead to campers' reports of social support.

### **The Author's Frame of Reference**

The author's involvement in understanding childhood cancer and impacts began in 1991 when his own child was diagnosed with leukemia cancer. As a result of experiencing treatment regimes and attending family camp, having two daughters attend sibling camp, and a son attend patient camp, the author developed some understanding of the value of cancer camp interventions. During graduate school studies, an opportunity arose to conduct an evaluation of Camp Grey Dove (CGD), a camp for siblings of children with cancer to identify the benefits of the camp experience to help justify requests to foundations for funding.

The author conducted an evaluation of CGD for two consecutive years. During the first year, the author observed camp and completed an evaluation for CGD. This initial experience was followed by a more intense effort the next summer to provide additional evaluation insights and pursue the study purposes defined in this thesis.

Chapter I has provided an introduction to the purpose of the study and a theoretical framework that helped guide this research. Chapter II follows with a review of literature covering the background of social support, social comparison, camp setting,



and particularly sibling camps. Chapter III provides a summary of the research methodology used to conduct the study with an outline of the steps taken to produce the qualitative results. Chapter IV presents the results of the study. Lastly, Chapter V presents a summary of the study findings, discussion of the findings, and implications for theory and practice, and suggestions for future research.

## **CHAPTER II**

### **LITERATURE REVIEW**

The literature is presented in five sections. Section one presents a discussion of the social support literature and the four elements of social support used to guide this research study. Section one also includes a review of how researchers have applied the social support construct to siblings of children with cancer. Section two examines how mechanisms of social comparison relate to feelings of social support. Section three discusses camp settings and the role these play in enhancing the well being of youth. Section four provides a review of research on sibling camps. Finally, section five ends with a discussion on a few selected studies of siblings of children with cancer.

#### **Social Support**

This study examines the role of social support on the well-being of children at camp. Recent scientific interest in social support was largely driven from the lectures of two distinguished epidemiologists with strong psychosocial expertise and interests (House et al., 1988). In 1976, John Cassel gave the Wade Hampton Frost Memorial Lecture to the American Public Health Association and the same year, Sidney Cobb gave the Presidential Address to the Psychosomatic Society. Both Cassel and Cobb reviewed extensive studies to demonstrate the centrality of social relationships and supports to the maintenance of health, emphasizing the potential of these mechanisms to moderate or buffer potentially deleterious health effects of psychosocial stress and other health risks (House et al.). These important lectures appeared to have influenced a shift

away from focusing research on siblings that studied the negative effects of the cancer experience to positive indicators of well-being for this group.

Social support, like stress, tends to be commonly understood in a general sense, but has had conflicting definitions when attempts are made to be more specific. House (1981) suggested that we all have an intuitive sense of what constitutes social support: we know people who we regard as “supporters” or “supportive” and that our parents are generally our earliest sources of support, and support is eventually expanded to include relatives, friends, spouse, children, church members, teachers, physicians and others. For example, in the children’s classic story, *The Wizard of Oz*, Dorothy received social support from the Scare Crow, Tin Man, Lion and others along her way to the emerald palace and once reaching the palace sought support from the Wizard himself. House (1981) would argue that the kinds of supportive inputs received from each of these characters were quite different, as were the outcome benefits received.

Social support has received substantial consideration as a mediator of the relationship between stress and adjustment in adults (e.g. Cobb, 1976; House, 1981) and more recently children (e.g. Murray, 1999). Cobb (1976) conceptualized social support as information leading an individual to believe he or she was loved, cared for, esteemed and valued, and belonged to a network of communication and mutual obligation. This conception lead other scholars (e.g., Barrera, 1986; Vaux et al., 1986) to focus their attention on the elements comprising social support, e.g., size of network resources and network membership identity; subjective perceptions or appraisals of support provided by network members; and specific behaviors provided by members also referred to as

“enacted support” (Dubow & Ullman, 1989). Barrera (1986) also argued that researchers should draw clear distinctions between the different aspects of social support in order to increase understanding of the role of social support in adjustment.

After almost a decade of study, House et al. (1988) asserted that their assessment of the social support literature was essentially unaltered:

Evidence that social support can reduce morbidity and mortality, lessen exposure to psychosocial stress and perhaps other health hazards, and buffer the impact of stress on health is now available from diverse types of studies: laboratory experimental studies of animals as well as humans, cross-sectional and retrospective field studies of human populations, and growing numbers of longitudinal or prospective field studies as well. Although the results of individual studies are usually open to alternative interpretations, the pattern of results across the full range of studies strongly suggests that what are variously termed social relationships, social networks, and social support have important causal effects on health, exposure to stress, and the relationship between stress and health (House et al., 1988, p. 296).

House (1981) suggested that one way of learning how to measure social support is to review a contrast between definitions within the scientific literature. Another was to consider obtaining a conceptual definition from ordinary people, a method intending to obtain face validity of the social support construct. House’s study began with a critical analysis of how social support had been defined in the literature, which led him to

conclude that scholars were sometimes vague, circular, and even contradictory in their definitions. House (1981) reported varied definition findings including:

- 1) Cassel's (1976) lack of explicit definitions;
- 2) Lin, Simeone, Ensel, and Kuo (1979) defining social support as support that is social;
- 3) Cobb (1979) referring to three aspects of social support as: (1) "emotional support," (2) "esteem support," and (3) "network support;" In his later paper, Cobb (1979, pp. 93-94) explicitly distinguishes social support from: (a) 'instrumental' support or counseling, (b) 'active' support or mothering, and (c) material' support or goods and services..." (p. 16).
- 4) Kahn and Antonucci (1980) defining of social support as "interpersonal transactions that include one or more of the following key elements: affect, affirmation, and aid;"
- 5) Pinneau (1975, p.2) distinguishing among tangible, appraisal (or information), and emotional support" and;
- 6) "Caplan who had written widely on the role of "support systems" in relation to stress and especially community mental health (Caplan, 1974; Caplan and Killilea, 1976) (House, 1981 p.15-17)."

House's was most influenced in his conceptualization of social support after he examined a study by Gottlieb (as cited in House, 1981), which led House to identify four broad categories of social support that have made his work seminal. The Gottlieb study involved semi-structured interviews with a sample of 40 single mothers receiving

social assistance in Canada. The study collected data by asking the mothers to identify problems they were experiencing and characteristic features of the person who had been helpful with helping them to deal with those problems (House, 1981). Taking formal (professional assistance), and informal (family, friends, coworkers) sources of support into consideration, House chose to focus on informal sources of support as these sources were seen as the most preventive forms of social support because they could preclude the need for more formal support or treatment. House concluded that:

Both scientific experts and relatively uneducated laypersons agree that social support is an interpersonal transaction involving one or more of the following: (1) emotional concern (liking, love, empathy), (2) instrumental aid (goods or services), (3) information (about the environment), or (4) appraisal information relevant to self-evaluation) (p. 39).

The current study was guided by House's conceptualization of social support. The following paragraphs provide more detailed definitions of the four areas of social support.

*Emotional support* involves the provision of trust, love, caring and empathy (House, 1981). It is important to note that emotional support probably has the most convergence with the four supportive behaviors or acts. In addition, both experts and laypersons tend to believe emotional support is the most important and is the most familiar of the defined supports (House, 1981). Prior to House breakthrough definitions, Pinneau (1975) defined emotional support as "the communication of information which directly meets basic social-emotional needs, for example: a statement of esteem of the

person, attentive listening to the person” (p.17). Emotional support is associated with sharing life experiences. It involves the provision of trust, love, caring, and empathy.

*Informational support* has been defined by House (1981) as: “providing a person with information that the person can use in coping with personal and environmental problems. In contrast to instrumental support, such information is not in and of itself helpful, rather it helps people to help themselves...Obviously, providing information may imply emotional support and may, at times, constitute instrumental support as in the case of tutoring or coaching vocational or academic knowledge” (p. 25).

Drawing a distinction between informational and instrumental support can be difficult. In contrasting the two, House noted that it is not that the information itself that is helpful but rather such information support helps people to help themselves. For the current study, informational support will involve the provision of advice, suggestions, and information that a person can use to address problems.

*Instrumental support* involves behaviors that directly help a person in need. Examples of instrumental support may include helping people perform school work, providing transportation to a destination, or assisting the individual with financial matters. House (1981) cautions his readers to be mindful that it is important to recognize, however, that a purely instrumental act may also have psychological consequences. For the purposes of this writing, instrumental support involves the provision of tangible aid and services that directly assist a person in need. Instrumental support is typical of supportive behavior or acts provided by close friends, colleagues and neighbors.

Lastly, *appraisal support* has been likened to informational support by House (1981) as it involves only transmissions of information, rather than the emotive affect involved in emotional support or aid involved in instrumental support. Nevertheless, information involved in appraisal support is germane to self-evaluation or what social psychologists have termed social comparison (Festinger, 1954). That is, as humans we share an innate drive to evaluate our emotions and abilities, and if there is no objective standard by which to compare ourselves, other people become sources of implicit or explicit evaluative information that individuals use to evaluate themselves (House, 1981; Meltzer, 2003). For the current study, appraisal support involves the provision of information that is useful for self-evaluation purposes: constructive feedback, affirmation and social comparison...

### **Social Support and Social Comparison**

Social comparison is processes by which individuals compare themselves upwards or downwards with like others. Meltzer (2003) explained social comparison as follows:

Upward comparisons occur when we compare ourselves with others who are better off. This gives us information as well as clues about successful coping, providing hope, motivation, and inspiration. Downward comparisons are a cognitive coping mechanism where people compare themselves to less-fortunate others in order to make them feel better about their own situation (although my situation is bad, at least it's not as bad as some other people) (p.8).



For instance, when viewing the world through a pessimistic lens, individuals look at other's positions as better than theirs, and begin to think they will never be able to achieve those circumstances, and thus begin to pity their current circumstances. When the pessimistic individual compares downward, they tend to perceive that their circumstances can only get worse.

On the other hand, when individuals view the world through an optimistic lens, they begin to internalize that if others can make it, then so can I. They experience hope and see the possibilities that exist beyond their current circumstances. When the optimistic individual compares downward, they tend to appreciate their current circumstances as not being worse. In other words, they look at those individuals in more difficult circumstances and sympathize with their current situation, because they know that things could be worse and at least they are doing better than someone else.

Meltzer's descriptions appear to depict that of the optimistic view. While this thesis will not investigate the differences offered by analyses of the two lenses, it may be important for future research to consider how a child's optimistic or pessimistic view may impact social comparison and perceptions of social support.

A seminal work on social comparison processes comes from Festinger (1954) who discussed how the theory applied to the appraisal and evaluation of abilities as well as opinions. Festinger (1954) noted data showed that when our evaluation of ourselves in private are unstable, then given an opportunity to compare ourselves with others, the comparison would have a considerable impact on one's self-evaluation. This has been found to be true in experiments involving both abilities and opinions where a person is

provided a series of trials in which the person is unable to compare performance results with others, than when scores of others are made available to compare, the person almost always shifts their level of aspiration closer to the level of the performance of others (Festinger, 1954). Festinger (1954) further suggested that to the extent an opportunity for self-evaluation does not exist, the drive for self-evaluation becomes a force that acts upon persons to belong to groups and associate with others. To quote from Festinger (1954): “People tend to move into groups which, in their judgment, hold opinions which agree with their own and whose abilities are near their own” (p.136).

In 2003, Meltzer extended studies of social comparison to camp settings. Meltzer’s (2003) study found that: “(a) Participants reported feeling more similar to camp peers than non-camp peers; (b) Adolescent participants reported significantly greater social acceptance when comparing themselves to camp peers versus non-camp peers; and (c) Loneliness was significantly predicted by how different children felt from non-camp peers (those who felt more different reported more loneliness)” (p. 7) .

### **Camp Settings**

Being in the outdoors can create an environment that avoids some of the pressures and stresses of a typical American lifestyle. Literature suggests that wilderness provides a positive connection with nature and self for all individuals. For example, studies have documented positive interpersonal developmental outcomes from wilderness challenge programs (Kaplan, 1977; Kellert & Derr, 1998).

Wilson (1984) suggests that there exists a biologically based, inherent human need to affiliate with life and lifelike processes and some scientists have that spending time in nature has natural restorative benefits (Kaplan, 1995).

Camps generally place individuals in settings where there is a greater opportunity for reflection, meditation, and solitude than can be achieved in a typical day at home. Camps provide an opportunity for youth from various backgrounds to come together and participate in activities that involve fun, laughter and creative thinking. Camps have been known for the intimacy of camp fire songs, inner tent play, and running around in a free-spirited environment. Structured camps provide an opportunity for exposure to activities and the development of social bonding through group process sessions. Camps generally have leaders or counselors who guide youth in their activities and support positive social interactions, team building and friendship nurturing.

In Martiniuk's (2003) discussion of camp programs for children with cancer and their families, the typical goals for therapeutic recreation interventions include the positive psychosocial outcomes of improving quality of life; developing emotional stability; increasing feelings of belonging; decreasing stress; developing feelings of competence; and self efficacy.

Although it has been documented as early as 1956 that research had been taken place on siblings of children with cancer, according to Hvizdala, Miale and Barnard (1978), the first camp for cancer patients was not established until 1978 and sometime later for siblings of children with cancer. Today, however, psychosocial support programs are now readily available to assist families dealing with the cancer experience.

Nevertheless, only a limited number of studies have investigated the efficacy of camps as one method of intervention for children with cancer, and even less address siblings. Martiniuk (2003) suggested that summer camps serving either children with cancer or siblings of children with cancer can produce beneficial outcomes due to their provision of social support. Jamison, Lewis, and Burish (1986) defined therapeutic recreation as the purposeful intervention designed to improve quality of life for the participant through recreation and leisure. The idea that recreation can serve an important function has been presented posited in the literature for some time. A number of researchers have suggested that leisure is believed to have beneficial consequences for psychological well-being and health (Caldwell & Smith, 1988; Chalip, Thomas & Voyle, 1992; Iso-Ahola, 1988; Iso-Ahola & Weissinger, 1984; Tinsley & Tinsley, 1986; Weissinger & Iso-Ahola, 1984). Authors including Freud (1955), Erikson (1963), and Bolig (1980) have suggested that recreation can help children develop adaptive coping skills that contribute to a better sense of well-being.

### **Sibling Cancer Camp Research Pattern Review**

Early studies of siblings of children with cancer focused on measuring self-concept and self-worth with an attempt to understand psychosocial problems. Most of the early research on siblings' responses to the childhood cancer experience was completed by researchers in the fields of medicine, psychology, and sociology (Murray, 1999). The earliest research focusing on the impact of cancer on other siblings was conducted by Cobb (1956). Based on parent reports, major impacts on siblings included feelings of loneliness, sadness, and loss of parental availability to siblings. Binger et al.,

(1969) later reported that in approximately half of 20 families studied, at least one or more of the well siblings showed significant maladaptive behavioral patterns indicative of coping hardships. The findings revealed that siblings developed somatic problems, lower school performance, and feelings of rejection, fear, guilt and severe separation anxiety; leading the authors to conclude that supportive therapy for siblings should become an essential part of the holistic approach to family care (Murray 1999).

These initial study findings led researchers to further examine negative effects experienced by the well sibling during the illness of the sibling with cancer (Cairns et al., 1979). Results of the Cairns et al. study and others further documented that siblings had adaptive needs that merited special attention. Spinetta (1981) conducted a three-year longitudinal study with a focus on the siblings in the context of, and in relation to, the family system. The author concluded that well siblings' emotional needs were being met at a significantly lower level than those of other family members.

Although research had identified many negative effects on well siblings, researchers began to identify positive effects as well. In an exploratory qualitative study, Kramer (1981) identified findings of increased sensitivity and empathy for the patient and other individuals, enhanced personal maturation and increased appreciation for life. Kramer identified three critical factors in facilitating adaptive outcomes: (a) siblings wanted information about the disease, treatment, and patient's condition; (b) open and honest communication was essential; and (c) siblings expressed a desire to be actively involved in the ill child's care (Murray, 1999).

Following Kramer, other studies began to explore both the negative and positive effects of cancer on the well sibling. Murray's (1999) review of the literature concluded that research aimed at identifying what interventions siblings of children with cancer perceive as supportive would be of immense value. This conclusion provided a connective bridge between the sibling camp literature with that of social support literature where House (1981) suggested that the method of using perceived support is the most appropriate procedure in initial efforts to understand the relationship between social support, stress and health.

### **Why Qualitative Research Method**

Much of the early research on social support and siblings of children with cancer seems to focus more on negative effects associated with this experience. Social support has been addressed historically by psychologists and epidemiologists with psychologists giving nearly equal treatment to the positive and negative effects of social support (House, 1987). Williams' (1997) conducted an extensive review of the literature on siblings and pediatric chronic illness covering a period of 1970 – 1995. His review included a synthesis of over 40 studies of which 10 involved siblings of children with cancer. In those studies involving cancer the pattern of study assessments were: use of standardized tools (n=6); use of semi-structured or structured interviews (n=3); and one involved a mix of standardized tools and interviews. Of the 10 studies, only one reported positive significant findings, a qualitative study by Kramer (1984) using structured interviews. Siblings were the informants and there was no control group. Positive impacts were increased sensitivity/empathy and personal maturation. In addition, there

were also negative findings in the study; increased sibling rivalry, anger, frustrations, feelings of rejection, guilt, loneliness, sadness, confusion, anxiety, lack of information and decreased family involvement. Caldwell and Smith (1988) suggested that leisure experiences may help overcome loneliness and thus contribute to people's well-being.

The current study used a qualitative approach to understanding better how sibling campers perceived social support. Rossman and Rallis (2003) have suggested that qualitative research (a) is naturalistic, (b) draws on multiple methods that respect the humanity of participants in the study, (c) focuses on context, (d) is emergent and evolving, and (e) is fundamentally interpretive. Although good assessment tools for measuring social support currently exist (Harter, 1985a; 1985b; Dubow, & Ullman, 1989), the characteristics of the camp experience that produce the outcomes are not clearly articulated. There is a need for studies to deal with the mechanisms that lead to the occurrence of social support. Thus, the purpose of this study is to conduct an interpretive analysis of what aspects of the camp experience lead campers to feel supported. This study should contribute to the theoretical understanding of how the experience of attending a sibling camp leads to increasing the well-being of a sibling under stress. Health has been defined in several different ways. Coleman and Iso-Ahola (1993) provided a narrow definition, which is consistent with a bio-medical view, which defined health as the degree to which people are not suffering from illnesses. However, Caldwell and Smith (1998) have suggested a broader, holistic definition in which health refers to a state of well-being which encompasses emotional, physical, social and spiritual health.

As the study is concerned with adolescent well-being, House et al. (1988) framework for research on structures and processes of social relationships in relation to health was considered well suited as a conceptual basis for this study. The goal of this thesis was to add to the body of literature by further examining the impact of the camp experience on feelings of social support and provide an interpretive explanation of what perceived aspects of camp lead campers to feel supported at Camp Grey Dove.

### **Studies of Siblings of Children with Cancer**

Asada (1986) conducted a study of self-concept of siblings of children with cancer to explore specific factors in personality, family environment, and family support systems which affect a well sibling's adaptation to the childhood cancer experience. Results of the Asada (1986) study found that although parents and teachers reported some maladaptive coping responses, siblings who had higher self-concepts and perceived having families open to communication seemed to have less difficulty adapting. These results suggest that camp settings that enhance self-concept and a well sibling camper's ability to communicate may lead to better adaptation in the home environment.

Sahler and Carpenter (1989) conducted a naturalistic study to evaluate the effect of a sibling camping program on the level of medical knowledge, perceptions of cancer, and participants' mood state. Campers were placed into situations that required independent and autonomous behavior fostered by peer-group interactions rather than through dependence on parental judgment or non-parental adult micro-supervision. The camp program included a combination of formal workshops, psychosocial support



sessions, and recreation. The study found desirable changes occurred in each of the three areas measured and were sustained at least three months after camp. The author concluded that siblings seemed to benefit from attendance at camp, but while camp was a successful component of a comprehensive approach to sibling adaptation to childhood cancer, it was not a panacea (Sahler & Carpenter, 1989). Limitations of the study were no control group, and low ratio of completed pre-and posttests.

Murray (2001) conducted a descriptive exploratory designed study to examine self-concept in siblings of children with cancer in a camp setting. Results demonstrated that well siblings who attended summer camp scored higher on a self-concept scale than well siblings who did not attend camp. The study involved the use of a control group to investigate the impacts of a program intended to impact siblings of children with cancer. The study also used a standardized measure and had an acceptable sample size.

In summary, evaluation of programs, camps or non-camps, for siblings of children with cancer appear to demonstrate short-term increases in self-concept, perceptions, knowledge about cancer, and mood states.

## **CHAPTER III**

### **METHODS**

This study was designed to explore how campers at a camp designed for siblings of children with cancer perceived social support and what processes occurred at camp that led campers to perceive feelings of social support. The study was guided by House's (1981) framework for research on structures and processes of social relationships in relation to health. Thus the specific research question was: what is the impact of the camp experience on feelings of social support and what aspects of camp lead campers to feel supported?

This chapter outlines the study methods. It is divided into six sections, including a description of: the Camp Grey Dove (CGD); Peaceable Kingdom Retreat; camp activities; study design; data collection procedures; and data analysis procedures.

#### **Camp Description and Subjects**

CGD is sponsored by Any Baby Can (ABC), an Austin non-profit agency. CGD is one component of the agency's support services provided for siblings of children and has operated since 1993. The camp runs seven consecutive days, split between two sessions, one for younger and one for older siblings of children with cancer. Study subjects include all siblings of children with cancer registering for one of the two, three and one half-day residential camps. During summer 2007 the first camp session was attended by 16 children ages 7 to 10 year old, while the second was attended by 15 children ages 11 to 14 year old. In most cases, the children served by the camp are from

families who were being served by ABC throughout the year. Camp consists of group counseling sessions and camp activities designed to:

- provide youth with a fun experience while at camp;
- help youth make meaningful connections with other siblings of children with cancer; and
- help youth deal with difficult issues and feelings in a safe and supportive environment.

The first half day of camp is reserved for orientation and recreational activities. Beginning the second day, daily afternoon psychosocial support sessions are facilitated by a social worker. During these support sessions, arts and crafts activities and group games are combined with discussions on stress and ways of coping. Also, daily recreational, trust building and challenge activities are facilitated by the Peaceable Kingdom Retreat staff.

### **Peaceable Kingdom Retreat for Children**

CGD is held at The Peaceable Kingdom Retreat for Children (PK) which occupies about 170 acres on the Lampasas River in Central Texas' scenic Hill Country (Peaceable Kingdom, 2008). The retreat was established in 1984 by Daurice and Jim Bowmer in memory of their grandson, Charles Bowmer Schreiner, V, who died of a heart ailment at 11 months and three diabetic grandchildren, it was originally a fishing day retreat for chronically ill children “Baby Charlie's Fishing Camp” (Peaceable Kingdom website, 2008). Peaceable Kingdom annually serves 6,000+ children with chronic illnesses and special needs between the ages of 3 and 22, along with their

families as a part of Peaceable Kingdom's mission is to be free to those whom they serve (Peaceable Kingdom, 2008). Therefore, the camp operates as a non-profit organization which seeks donations to make sure that children are allowed to attend camp free of charge and without regard to race or, religion. Although 75% of the usage is strictly for the retreat's target groups (chronically ill and special needs children), PK also allows other groups such as church groups, civic organizations, businesses, and other groups to use the retreat so that the retreat can benefit from the partnerships that are developed (Peaceable Kingdom, 2008). ABC, an Austin non-profit agency and sponsor of CGD, benefits from having a partnership with a well established camp site with trained staff. Without this partnership, CGD would struggle to exist due to their lack of resources making owning their own camp prohibitive.

The lower end of the PK property is a forested area with man-made trails. Trails lead to outdoor adventure locations which include both low and high challenge elements. There also are horse grounds and an archery field location for group activities. The lower end rolls up through hill country areas that afford healthy hiking opportunity. A campfire site is located in an area that oversees the river.

The upper end of the property contains a more developed camping area. The owner of the camp has a primary residence in this area. There is also a large cafeteria building which doubles as an assembly hall. Two large livable cabin quarters (administrator cabins), complete with kitchen, large restroom, living space, and two large open bedrooms are also located in this area. CGD uses these cabins to house the camp director, social workers, a camp nurse, and the camp evaluator. There is also a

cafeteria building which serves as a natural play area and can be used for outdoor adventure facilitation. A swimming pool is located in a gated area behind the administrator cabins. The pool area can be used for a pool-side barbeques. A talking bird, which aptly refers to himself as “pretty bird,” is caged within the enclosed pool area.

There are two cabins for campers a small distance away from the main area along a cemented walkway that leads to the upper end of the property. The CGD campers reside there during camp. The cabins are segregated by gender.

The upper end of the property also houses basketball courts, a miniature golf course, and an historic cabin. There is also a theatre that provides a variety of entertainment opportunities for campers and administrators. A movie theatre, table hockey, pool table, arcade games, and a snack bar are all available for camper use. There is also a lounge area for campers to use during down time.

### **Study Design**

The researcher attended the entire camp and took on the role of an observer of camp activities. The researcher also had access to the children attending the camp so interviews could be conducted. In addition, the researcher was able to participate in informal conversations with campers throughout camp.

The researcher developed a protocol for collecting data that was based on the social support and social comparison literature and from discussions during meetings with camp administrators over the several months leading before camp began. Qualitative data were collected through observations, interviews, and journaling.

Approval from the Texas A&M University Institutional Review Board (IRB) was obtained before beginning the study. Consent forms were prepared in English and ABC mailed out packets of registration information to families prior to the beginning of camp. Packet enclosures included a letter describing the study, a parental/guardian consent form, and a camper assent form.

Four male and four female campers were selected for in-depth interviews. Efforts were also made to interview these same individuals approximately two months after the conclusion of camp. The selected campers were each interviewed on the evening of the third day of camp. The interviews lasted approximately 10-15 minutes. Interviews were held inside the administrator's cabins in an open room setting and were designed to gain in-depth information about campers' experiences during both at home and at camp and processes they perceived as critical to engendering feelings of social support. A copy of the interview guide is included in Appendix A.

### **Qualitative Methods**

Participant observations of camp and semi-structured interviews with selected campers were used to help gain insights concerning the impact of the camp experience on siblings of children with cancer. Journaling was also used to record observations undertaken during camp.

Miles and Huberman (1994) suggest several schemas for recording insights gained through the participation observations. The method of participant observation evolved from cultural anthropology and qualitative sociology as an overall approach to inquiry and data-gathering and has become an essential element of all qualitative studies

(Marshall & Rossman, 2006). According to Marshall and Rossman (2006), participant observation requires first hand involvement in the target setting, in this case Camp Grey Dove, as immersion offers the researcher an opportunity to learn from a direct experience of the camp setting. Experiencing camp first hand provided opportunities for personal reflections which were integral to the emerging analysis of this sibling group, and afforded new vantage points and opportunities to make the strange familiar and the familiar strange (Glesne, 1999).

During the current study, analytic memos were recorded as a way of noting behaviors and interactions as they occurred at camp. In addition, the researcher kept written notes and created reflective memos describing thoughts and insights gained through observing the camp (Wolcott, 1994). Analytic memos included the noting of observations that appeared to have a literature fit with social support and reflective memos included the researchers periodic summarizing reflection of what had been experienced by the campers and participant researcher.

Interviews are a widespread method used to conduct qualitative research. For the current study, phenomenology guided the study as the lived experiences of campers in the CGD setting were explored. A phenomenological approach lent itself well to this study as we sought to better understand their perceptions of how campers come to feel supported at camp, and their collective shared experiences could be narrated (Marshall & Rossman, 2006). The focus of the author's phenomenological inquiry was to describe the camper's essential experience with the phenomenon of social support. This approach was used, while bracketing off the author's experience and observations at camp from

those of the interviewees to gain clarity from developed preconceptions. This *epoche* approach was an ongoing process as needs for further inquiry or elaboration emerged during interviews (Patton, 1990).

Interviews were coded to understand how camp elements led campers to perceive social support. The interview transcripts were coded using the social support framework provided by House (1981); i.e., emotional, informational, instrumental, appraisal support). While the coding structure was guided by the tenets of social support, open coding was also done to allow other themes to emerge based on the lived experiences of youth and their counselors

After coding the data, a second step involved placing the codes into the transcripts. This process provided a second review and accounted for participant responses that appeared to convey more than one type of support or an emerging theme. To enhance trustworthiness, it is important to protect against one-sided interpretations, therefore the researcher read and re-read the data to determine appropriate themes and coded the themes (Henderson, 1991). This process also involved identifying salient themes, recurring ideas or language, and patterns of beliefs or perceptions that linked campers and the camp experience setting. This process allowed categories to become containers into which segments of text were placed (Marshall & Rossman, 2006). The researcher's advisor reviewed the themes and categories yield by this process.

After the transcripts were coded, all coded responses for each interview set were merged. Then patterns in the coded data were identified. Emphasis was placed on exploring why social support was occurring by seeking to understand and linking what



occurred at camp that led campers to perceive social support. An additional focus included examining House et al. (1988) suggestion that it is also important to study when, how, and why main effects and buffering effects occur. Quotations from interview texts were coded based upon social support construct defining characteristics, literature fit, and themes and subthemes that emerged. As categories of meaning emerged the researcher searched for those that had internal and external convergence (Guba, 1978).

Patterns emerging from the responses were noted and then organized into categories. Individual, group and total responses were analyzed to find major and subthemes. Interpretive coding was used to help focus on abstract issues and causal conditions (Patton, 2002). An attempt was made to build a story that identified the connection made in findings with theoretical propositions associated with social support and more recently social comparison as posited in the literature.

In summary, this study produced findings from an interpretive analysis which utilized both an inductive and deductive approaches. A deductive approach was used to gain a better understanding of how campers at CGD perceived social support on their terms. An inductive approach was then used for the purpose of applying the perceptions of social support, provided by campers, to seek to understand how the structures and processes of social relationship in relation to health were being linked at camp. An inductive analysis of data is provided in Chapter IV to discover patterns, themes and categories in the collected data (Patton, 2002).

## **CHAPTER IV**

### **RESULTS**

#### **Introduction**

Thirty-one children attended CGD, 14 in session one and 17 in session two. Parents of two participants in session one and three in session two did not give their consent for their child to participate in the study. Thus, precautions were taken by the researcher to not include these individuals in notes during observations or select any of these individuals for interviewing.

Twenty nine percent (29.2%) of the campers were 7-10 years old and 70.8% were 11-14 years old; 50% were females and 50% males; and 54.2% of the children had been to camp before, with 64.4% of these attending the previous year. 50.0% of the campers were Hispanic, 20.8% % were White, 12.5% Black, and 16.7% were characterized as other. Pseudonyms for the eight campers interviewed, along with gender, age, prior CGD camp attendance, and status of ill sibling at the time of camp are provided in Table 1.<sup>1</sup>

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<sup>1</sup> All campers were given pseudonyms to protect their identity. Coding at the end of quotes provides information to enabling tracing the quotes back to the original interview transcripts.

*Table 1: Interviewee Background Information*

Pseudonym Name	Gender	Age	Attended Prior CGD Camp	Ill Sibling Status
Jack	M	9	Yes	Off treatment 11 year old brother
Kathy	F	9	Yes	Off treatment 8 year old brother diagnosed at 2 ½
Angel	F	10	Yes	Deceased Older Sister
Roderick	M	10	No	Off treatment older sister
Tabithia	F	12	Yes	Deceased older brother at age 6 when she was age 2
Aaron	M	13	Yes	Off treatment 13 yr old twin brother
Jimmy	M	13	Yes	Deceased older brother at 16
Selena	F	14	No	Deceased recently younger brother age 6

This study was designed to explore how campers perceived social support and to understand better the processes or mechanisms occurring at camp that bring about reports of social support. While analyzing how the camp experience led siblings of children with cancer to perceive social support at camp, the following themes emerged regarding the types of social support identified by campers and how social comparison helped facilitate these feelings.

- Emotional Support
  - People are encouraging at camp,
  - People are nice at camp,
  - Camp provides an empathic support system, and
  - Campers are able to express their feelings.

- Informational Support
  - Clarification of ill sibling's condition and
  - Clarification that provided adaption skills for camper.
- Instrumental Support
  - Helpfulness,
  - Coping Skills, and
  - Thoughtfulness.
- Appraisal Support
  - Ability to relate,
  - Empathic environment, and
  - Safe and supportive environment.
- Social Comparison
  - Able to be empathetic,
  - Sense of belonging,
  - Sibling Club and
  - Able to talk or express feelings.

Although the data confirmed the four kinds of social support defined by House, there were a few subthemes that cut across support types.

### **Emotional Support**

There were 24 instances of emotional support that emerged from the camper interviews. Of those 24, 10 involved some expression of encouragement, cheering on, or supportive behavior. There were five instances of camper's perceiving others at camp being nice or not mean, and four instances dealt with the ability to express feelings. Finally, five instances included comments referencing others (e.g. spiritual support). Thus, four emotional support subthemes were identified from the reported expressions of campers: 1) People are encouraging at camp, 2) people are nice at camp, 3) campers are able to express feelings and 4) camp provides an empathic support system.

Campers indicated that group sessions were a time when they felt supported and were able to talk about their feelings. The themes of perceiving encouragement; people being nice; an empathic environment; and being able to express feelings were embodied in Jim's explanation of the benefits of the group sessions at camp;

“[Sam]: What is it about the group sessions that make a difference for you, that make it work for you?

[Jim]: Just being able to talk about my feelings.

[Sam]: What happens in group sessions that make you feel comfortable to talk about your feelings?

[Jim]: Um...the counselors can relate to us. They're nice to be around, and we did a lot of fun activities.” [1-C5AC]

#### *People Are Encouraging at Camp*

Ten camper quotes discussed receiving some form of encouraging feedback from others at camp. Both counselors and other campers reported perceptions of others cheering or congratulating campers. It appears that campers equated receiving emotional support with an act of encouragement from others that led them to feelings of affirmation. At camp, counselors played a key role in facilitating groups and remaining emotionally connected to children through their encouragement. Counselors modeled cheering and supportive behaviors throughout the activities.

Counselors encouraging campers during their participation in challenge activities is considered a normal practice at most camps. What appeared to be a distinguishing characteristic of emotional support at CGD was that campers perceived that

encouragement during activities came from everyone and was not predicated on winning or achievement, or the camper's willingness to participate. The camp norm was that campers had a "right to pass" or not participate in activities, a principle that social workers established in the initial group process sessions. In the group sessions campers learned that they could reserve the right to pass on participating or self disclosure. Thus, campers were empowered with a right to choose when faced with a challenging or uneasy circumstance. This right enabled campers to have some control over participation in contrast to their home environment where an ill sibling's care was likely to have become a factor in their ability to participate in free-time activities. Many of the campers reported having limitations on their social interactions at home as a result of a sibling's illness.

Campers were observed exercising their right to pass in group session more on principle rather than uneasiness. A returning camper was usually the first to exercise this right. New campers witnessed this modeling and appeared comfortable exercising their right to subsequently pass during group session or when participating on the challenge courses. While campers freely exercised their right to pass, they were still rewarded with affirmation for having the courage to make that decision. This was keenly illustrated when camper Ro shared what he credited as making him most feel supported at camp:

[Ro]: Like, 'you can do it, you can do it, climb!' but if you don't climb it and you go back down, they'll still congratulate you. [1-C3AC-1]

In this exchange, Ro is explaining the participation-by-choice principle that respects each individual's right to pass. Again, this principle is established early on in group sessions by experienced social work facilitators.

The researcher's observations also provided instances where campers, while not exercising their right to pass, sought to only confirm their right to pass exists. These instances are illustrated by the following example from the researcher's observation notes:

Next, we were provided with 5 stars and asked to place names on them that represent our source of support and then be prepared to share. Jared asked, "Can we pass?" Stephanie replied, "yes, and do you wish to pass?" Jared replied no but he was just checking to be sure. Stephanie reiterated that members may always pass at any time. We each describe another person. Session was adjourned by working through the dance routine naming everyone again. (Observation: This was a comfortable group. There were sad faces, smiles, shy faces, comedy but all were respectful of the process. Thought this was an excellent group forming meeting that allowed group members to feel each other out. It was interesting how Jared enjoyed testing the pass rule. Seem to provide a sense of control. [27q-OBS2])

The CGD experience provides an opportunity to participate in a variety of activities with the controlling factor being the camper's own initiative. For those who had a reduced expectation of having the freedom to choose, camp provided an opportunity to re-establish self-interest. Campers were encouraged to participate by cheering counselors, supportive peer campers and the role modeling of challenge play participation by CITs and counselors. As shared by Ro, there is no ridicule associated with not participating.

Campers were also encouraged to set personal goals and try new things. Some campers found themselves competing for attention at home from parents and others who

seem to direct most of their attention toward the ill sibling. However, through supportive encouragement, campers learned at camp that the camp experience is for and about them. Thus, campers who initially were caught up with thinking about their ill sibling rather than utilizing the opportunity to think about and enjoy themselves while at camp were given permission to be a little bit selfish. This enabled campers to free themselves emotionally from having life centered mainly on an ill sibling. As a result, campers were taught to not be concerned about competing against others, but to challenge themselves to experience their own personal limits. In quotes from Aaron, we can see how encouragement by PK staff of setting attainable goals led to his ability to transfer a coping skill into future initiative:

[Aaron]: ...At first I didn't want to do the rock wall, and then they said set a goal for yourself so I said I'd just go half way... [1-C8AC-1]"

[Sam]: ...Why? Why do you think they encourage you?

[Aaron]: 'Cause they probably want to help us grow up, and conquer our fears.

[Sam]: Did you conquer any fears this year?

[Aaron]: Yeah I did the rock wall. And the giant swing.

[Sam]: And the giant swing...that's more than you did last year? What is your goal for next year?

[Aaron]: To do the zip line and the rest of the rock wall. [1q-C8AC]"

### *People Are Nice at Camp*

Probably the most illuminating discovery during the researcher's time at camp was identifying the campers' perceptions that people were nice. This norm of nice is



consistently shared and expressed as a language of the campers and was also expressed by the adult leaders. Several CIT's expressed feeling a need to be nicer to their siblings when they got home from camp. Through the interviews and observations, noted comments were identified as having to do with a perception that people were nice at camp.

CITs recalled that when they were campers someone assisted them and thus they returned to camp with a commitment of passing on the kindness to other campers. Other campers began adopting these norms of being nice and giving back during their camp experience as illustrated by Angel during an interview exchange;

[Sam]: So did you make any friends at camp this year?

[Angel]: A whole bunch.

[Sam]: A whole bunch!

[Angel]: Yes, and the new people, I cheered them on and said don't be scared because I've been there last year, and its just more fun if you know more people and that's how I learned.

[Sam]: So by supporting the new kids you became their friends?

[Angel]: Yes, and some of the kids last year, I already knew them. And I helped them, and if they were my friends and they were new I would introduce them.

[Sam]: And is that what kids did for you last year?

[Angel]: Yes.

[Sam]: So now you're returning the favor.

[Angel]: Yes. Cause my friend, she moved on to being one of the older kids so she helped with my friends. [1r-C4AC]

Using the word nice seems to be a common expression of campers' perceptions of supportive behaviors such as being encouraged and cheered on, and through other social interactions. One camper delineated a line between friends in camp and friends at home, with kids at camp categorized as not being mean. While emotional support seemed to be expressed in terms of encouragement, ability to express feelings, people being nice and other empathic support, the perception of what is memorable to a camper was expressed by Kathy when she said:

[Sam]: Did they do something for you that was really memorable, that you needed? [Kat]: They just, nothing that they did really stands out, but they're really nice. Everybody here is really nice. 3-C2AC-1)

Outside of group sessions, campers appeared to have an unspoken awareness of the inner struggle they had to endure as a sibling of someone with cancer. Rather than spending a lot of time expressing sympathy or pity toward one another, campers engaged in the activities with zeal which appeared to lessen the burden of stress associated with being back home. Through these processes, they were able to return to "just being a kid."

### *Campers Are Able to Express Their Feelings*

Ability to express, explain or talk about one's feelings was reported by campers as an expression of perceived social support at camp. In three of four instances where this occurred, campers related their experience to opportunities to express their feelings

in group sessions. The experience of expressing feelings in sessions also manifested itself during cabin time and non-verbally during challenge activities. The ability to express one's feelings in social relationships is a behavioral coping skill mechanism which according to House (1988) may facilitate individual behaviors that are promotive of health or protective of health in the face of stress or other health hazards. In essence, opportunities for catharsis can have a buffering effect on feelings of stress by helping to facilitate psychological and behavioral processes of coping and adaptation in the face of stress (House, 1988). These processes were illustrated by a camper in his attempt to explain how CGD differs from other camps in its offering of group session opportunities:

[Jim]: It (group sessions) helped me talk to say my feelings; it felt like weight was lifted off my shoulders. [1qr-C5AC-4]

On one occasion during camp, the researcher observed a camper wander away from other campers who were participating in a fun group activity on the cafeteria patio. The researcher approached this camper during lunch and learned that he perceived that he had no friends at camp. With encouragement, the camper and the researcher identified a way to join the other campers for lunch. The following is from the researcher's observation notes regarding this situation:

[Noticed Nicolas not eating]. Nicolas asked if he would eat with me. We talked about importance of nutrition to avoid fainting in the heat. He seemed down. Nicolas agreed to eat with me. Nicolas chose to sit in the back away from the other kids on the arts and crafts table where the Peaceable Kingdom staff dined. Shared how he had not made any friends but wanted to. I convinced him to go over to fill an empty space at a table of other male campers to blend in. Nicolas then suggests, "Yeah, and then I can make some friends." We picked up our

plates and went to sit with a group of boys and a PK staff counselor. We integrated into the conversation. [3-OBS1 12:30 Pm Day 2]

The supportive environment at camp contributed to others reaching out to this camper and the inclusiveness of camp allowed the camper to eventually experience social support. The following are some observations the researcher made during cabin activities regarding Nicolas, a 7 year old camper, struggling to overcome feelings of isolation:

Campers rotated through showering and bed preparation. Game playing began to take place with flash light tag as the game of choice. As showers were completed, more joined in. A camper (Nicolas) without a flashlight said, "I'm going to bed so don't flash the light on me because I'm not playing?" Time and time again, this request was ignored. Finally, the camper said, "that's it, I'm playing now!" He joined in helping to spot hiding campers. Eventually, he was loaned a flashlight and became a full member of this game. [10-OBS1 10: pm Day 1]

Overall, Nicolas arrived at camp perceiving that kids at camp would repeat the isolation from similar others that Nicolas experienced at home. Nicolas struggled to overcome his lack of social interaction skills with his peer age group. The flash light game was open for all to participate. However, the kids seemed so starved for peer group fun that they tended to ignore feeling sorry (sympathizing) with others that did not participate by choice. Again, kids began to understand that it is okay to be a kid and the freedom to relax becomes contagious. There were several instances of campers exercised their choice to withhold from joining in, only to dive in later as they observed the happiness of others. Thus, campers made breakthroughs that allowed them to rediscover, in some instances discover, the joy of being a worriess kid. Being empathetic did not require feeling sorry for Nicolas. Campers were willing to afford

space to allow an individual to process what was holding him back. In this empathic environment, encouragement eventually occurred and allowed Nicolas to not remain in seclusion too long. Nevertheless, the choice to come out of isolation remained with the camper.

### *Camp Provides an Empathic Support System*

Social bonding occurred at camp and was facilitated by campers being in the presence of similar others. Five statements by campers related to camp providing an empathic support system. These statements involved perceptions of receiving some form of affective support. There were meaningful relational connections made between campers, as a result of their similar experiences, that allowed campers to reach out to each other in multiple ways. The following quote, illustrates how a camper was receptive to spiritual counseling from another camper:

[Tab]: I talk to one friend, Bernice. And she'll just tell me its okay and just be proud that he is in Heaven and at least he got to live a little bit.

[Sam]: Does that make you feel better?

[Tab]: Very, it makes me a lot better. [1-C6AC]

Campers perceived that their similar experiences allowed them to understand each other in a way that was not possible outside of camp. Campers appeared less amenable to expressions of perceived sympathy at home while being more receptive to the perceived empathic support that occurs during their CGD experience. Statements by both Tabithia and Selena illustrate this point.

[Tab]: ...if like I say I feel bad because my brother passed away and I'm upset and I still think about it, they'll say "oh yeah, Tabithia's brother passed away" and I don't like that. [1-C6AC]

[Sam]: Was this different than the support you have at school, or at home, I heard you say you had support at home.

[Selena]: Well I think they support me more because everybody knows what I've gone through...and they can relate to that.

[Sam]: Here at camp or at home?

[Selena]: At camp. (1q-C7AC)

Group sessions were facilitated by two social workers skilled at creating opportunities for catharsis among campers. While group sessions were often cited as a venue for emotional support, it was commonly acknowledged by social workers and CITs that it is typical for several campers to have an attachment to a particular counselor and cling. These one-on-one interactions were perceived as immensely supportive by campers. For example:

[Angel: When I was talking to Ms. Meridian, I could explain how I felt to her and also to my friends how I felt." [1q-C4AC-1]

### **Informational Support**

Informational support deals with the process of clarifying misunderstandings. There were four instances of informational support that emerged from interviews with campers at camp. Two involved information that provided clarification or

understandings involving the ill siblings condition and two involved information that enabled clarification or understanding that provided beneficial adaptation skills for the camper. Of the four, only one instance developed both clarification and adaptive skills.

Campers were asked if anyone at camp had given them direct assistance or information that had allowed them to solve a problem or had provided them with help while they were at camp. Campers tended to struggle to come up with specific instances, thus being more general in their responses. This may explain why only four instances emerged. It also appeared that the camp did not focus on directly providing information about cancer or how to cope with having cancer in campers' households. Providing this information was more likely to occur outside of camp when campers and their families were receiving support services during the year through Any Baby Can.

While CGD's objectives did not focus on improving sibling camper's cancer I.Q., it did help them process their concerns about cancer. However, where camps have emphasized providing cancer information, positive results have been noted. For instance, a study by Williams' (1997) provided beneficial information to sibling camp organizations seeking to strengthen the learning aspect of informational support at camp. Williams' (1997) case study reported that a camp intervention effort combining structured teaching about ill sibling's diagnoses, psychosocial sessions, residential camp, two booster sessions and parent sessions, showed significant improvements on outcomes measures of knowledge about illness, behavior problems, social support, self-esteem, attitude, and mood measured over four post-intervention periods. However, individuals

participating in partial intervention (camp only) and control group (camp only waiting list after last data collection) did not show the same outcomes.

By sharing experiences, CGD campers developed adaptive skills by making the connection between “you’re okay,” “I’m okay” or “I’ll be okay”. In one instance, a child was able to overcome feelings of depression and console her family regarding the potential harm of being depressed.

[Angel] “Because when my sister had just passed, and my grandma and my family wasn’t eating. But when I came to camp, I learned that depression could really hurt a family, and I just talked to my grandma and grandpa how I learned that when you love somebody and they pass, you can move on, but not really fast. And they would want you to live longer and stay happy with your family.”

[2q-C4AC]

In another case a sibling held some misconceptions about camp and did not wish to attend. However, a CIT recognized the camper’s apprehension and approached her during the bus drive to camp. The CIT was able to provide some insights about camp by sharing her prior experiences. This reiterative process of wanting others to experience the joy that was previously experienced by the CIT when she was a camper was common among the CITs. Observations of this camper, Selena, and comments shared by others, showed that she started with an apprehensive approach to camp. However, as encouragement continued, she came to feel that everybody at camp was supportive and she declared that camp was fun! Thus, the conversation on the bus may have overcome some of the apprehension being felt by this camper.



In the current case, a camper came to camp frowning in anticipation that camp would not be a fun experience. Selena's potential self-fulfilling prophecy appeared to have been overcome by the CIT's comforting words. Selena's restrictive home environment was limiting her ability to envision what the CIT was trying to describe. However, Selena was soon introduced to a supportive environment she had no idea existed. Her home environment had been dominated by her sibling's illness and eventual death. Providing parenting assistance to her infant sibling and limiting herself to in-home social interactions when not at school were stifling for her. The informational encouragement she received on the bus also provided emotional support to this camper, and was instrumental in her being able to loosen up, try new things, and be receptive to supportive others at camp. Selena shared the following;

[Selena]: She was like 'you're going to have a lot of fun at camp here'. And 'cause I didn't really want to come here in the first place, but she told me everything we were gonna do like the ropes course and horseback riding, and told me it would be lots of fun, and it was. [2q-C7AC]

[Selena] "It's nice here, because I feel like everybody is supporting me in whatever I do."  
[1q-C7AC]

In the two other instances, campers reported receiving informational support that clarified a misunderstanding or provided information about their sibling's illness. Although the information pertained to the sibling's illness, one instance indicated a direct lessening of a burden for one camper as illustrated by Tabitha's commenting on how a counselor had helped her at camp:

[Tabithia] She tells me that it's okay, but that it's not my fault that he passed away and that I shouldn't feel like it was all my fault because....I don't know what we talked about....but yeah, it wasn't my fault but that it just happened. [1-C6AC-1]

It appeared that informational support was provided from a variety of sources at camp, e.g., a counselor's clarification of a misunderstanding; informative information from ABC about chemo-therapy treatments; expressed appreciation for the potential harm from depression learned from other campers shared experiences in group session; and informational support received from a CIT on the bus ride to camp. Thus, informational support appeared to be operative in different settings throughout the camp experience. In addition, there appeared to be a cycle of willingness to share information, among camp participants, for the benefit of others.

Informational support was intertwined into the social interactions that occurred at camp. These interactions had the potential to lead to developing social adaptive skills and enhanced camper well-being. For example, informational support directly impacted a camper by helping her remove feelings of guilt associated with a deceased sibling. The camper became able to articulate an awareness of her non-fault which she credited to support received through personal counseling received from a counselor at camp. In three instances, informational support served as a buffer by lessening the burden of stress related to feeling at fault, depression associated with a sibling's illness and negative expectations about experiencing fun at a camp while grieving over a loved one.

Here, Angel describes how she has been able to derive a psychological coping mechanism, over time, from camp:

[Angel]: They had the same thing going on as my family, and they would tell me that depression can really go somewhere, and really hurt someone very bad and they just helped me more and more, every year, they just helped me understand more. [2q-C4AC]

### **Instrumental Support**

There were 30 noted instances of instrumental support that emerged from interviews with campers. Twelve (12) were instances of others being helpful; 9 were instances of perceived enhanced coping skills; 4 were instances of others being perceived as being thoughtful; and 4 were some combination of prior subthemes.

The data provided insights about whom or what campers perceived as their source of support. In 10 of the 12 instances camp was identified instrumental in the camper's perception of developing a coping skill. Three instances involved a counselor as the source of support. When helpfulness was reported, counselors were most cited as a supporter. In contrast, other campers were most cited when instances of someone being thoughtful were reported.

Based on the analysis of the interviews, three primary themes, each with subthemes, emerged to explicate how campers perceived instrumental support at camp: 1) helpfulness, (2) coping skills and (3) thoughtfulness.

### *Helpfulness*

Campers perceived that people were helpful at camp. Campers cited examples of someone providing direct assistance or help by doing something specific for them.

Examples ranged from a counselor helping to get a Frisbee off the roof to another camper sharing some lotion. Helpfulness was further illustrated when Kathy said: “I remember one time I got lost here, and a counselor helped me. They helped me find my way when I got separated from my group, and they helped me.” [3-C2AC-1]

Two subthemes emerged from helpfulness were: 1) Supportive others willing to assist and 2) Group sessions facilitate instrumental support.

*Supportive Others Willing to Assist.* According to House (1988), the provision of time and materials are some of the ways that instrumental support can be defined. There were 10 instances of campers reporting they had been provided with some time or material from others at camp. Time provided by others which was perceived to be instrumental included a one-on-one counseling discussion; directions received from a counselor while lost; another camper taking time to share helpful advice; assistance with questions or arts and crafts; and a CIT taking time to provide a camp newcomer with helpful anxiety-reducing information about the expected camp experience. Angel said the following about how she received some direct assistance: "Oh yes. Like when we were doing the arts and crafts and I didn't know one of the counselors came and helped explain how to do it." [3-C4AC-1]

In describing direct assistance, campers recalled instances where there was a need for immediate assistance. When describing being lost at camp, one camper did not

seem distressed by this occurrence. The watchful attention of an alert counselor guided the camper back on course. Another aspect of instrumental support was relational, e.g., campers perceived they had developed an ability to express feelings and communicate with others they were able to relate to at camp. Trust was facilitated by the confidentiality developed in group sessions and continued throughout the camp experience. This ability resulted in perceptions of learned coping skills that campers appeared ready to try out when they returned to their home environment. This suggests that the camp experience could have impacts beyond the time at camp.

*Group Sessions Facilitate Instrumental Support.* Group sessions facilitated opportunities for campers to share experiences that provided an understanding about their own situations without having to be the center of attention. As campers developed a sense of commonality, they seemed to mature in their willingness to share at camp. Willingness to share in group sessions for the benefit of others became a learned skill as campers observed counselors and other campers showing adherence to the camp's norm of "participation-by-choice." Campers tested this norm simply to confirm their right to choice, yet subsequently participated fully in the discussion activity. For example, one camper "passed" on a simple question, yet was comfortable responding to a more difficult and sensitive question. This observed experience appeared to be a form of resistance to the home environment where leisure free time choices were possibly limited by the ill sibling's health care priorities. At camp, there appeared to be ownership of a sense of control that emanated from the camp norm of having a right to "participate by choice". Although campers were empowered with a right to pass,

campers appeared to freely choose to share their stories and learn coping skills through participation rather than abstain from involvement in discussions or activities. The desire to participate became infectious because the activities moved on without you and campers quickly learned that it is the opportunity to participate, not the opportunity to resist that brought them to camp. Nevertheless, it is having the power to resist that gives campers a sense of autonomy at camp, an empowerment not otherwise afforded in many instances at home.

### *Coping Skills*

Two subthemes emerged to explain coping skills: 1) Ability to express feelings and communicate, and 2) Cognitive awareness.

*Ability to Express Feelings and Communicate.* Story telling enabled sharing of feelings of isolation and jealousy, and afforded opportunities for campers to discover the universality that exists within each camper's story. As campers learned others' stories, an empathic environment was established and carried over into the camp experience. A sense of belonging intensified once campers began to perceive that they were in the company of similar others. Campers learned that those similar others had similar experiences, feelings, family circumstances, and consequently, similar stories to share. In the following quote, Angel indicates that she was comfortable expressing her feelings at camp: "Because I can let them out, to a lot of people. Here at camp. And I just feel like I can really relate to them and they help me understand more and they just really help me." [3r-C4AC-3]

The camp experience appeared to have some degree of transference into the campers' home environment. The ability to express feelings in camp served as an instrumental practice platform for social interactions outside of camp. For some, this equated to enhanced communication with family members, for other it expanded out to friends and others. As Kathy said: "It made me comfortable to talk about my feelings about cancer with all my friends, 'cause I could do it here, so I could do it, like, with my feelings at home." [3-C2AC]

It can be deduced that Kathy's perceived comfort at camp had a buffering effect on her ability to express her feelings at home. At camp Kathy, like Angel, learned to open up and express her feelings. The experience of catharsis released tension and allowed the campers to more freely enjoy activities. They learned to decrease their stress levels so that they can enjoy the hear-and-now of the moment (Yalom, 1995). Trust was built at camp through activities which required dependence on team members to work jointly to solve challenges. Trust was also built in group sessions where confidentiality was a socially accepted norm among campers. Communicating with group members or team members was critical to the success of each activity. Campers learned that communication, not silence, was essential to developing trust with people who were perceived as our team members (family). Selena said the following as she came to understand this principle:

[Sam]: Do you think being at camp will help you talk more to your parents?

[Selena]: Well I hope it will, because I know that I have to talk to them because it's important.

[Sam]: To communicate?

[Selena]: Yeah.

[Sam]: Where did you learn that communication is important?

[Selena]: In our groups, and by doing the activities. [3-C7AC-2]

*Cognitive Awareness.* Campers reported learning adaptation skills like staying within their comfort zone and by learning the importance of talking to others about their circumstances. Campers also learned delayed gratification and resistance to peer pressure skills. Campers learned to discuss their sibling's illness when others inquired or how to decline the opportunity depending on their comfort zone at the time. Some campers struggled with this issue at home because they were not always considered an “informed family member.” A prevailing wish among campers seemed to be that they would prefer to be an “informed family member” or an active part of caring for their ill sibling. Being protected from the knowledge of a sibling's condition did not seem to sit well with campers.

Interestingly the participant interviews may have become instrumental for the interviewees as the interview sessions may have provided an opportunity to reflect more deeply about how camp had been supportive and what adaptive skills had been acquired. Campers articulated a cognitive awareness of the problem solving skills they had learned. For example, Aaron shared what he had learned at camp:

[Aaron ]: Um, I learned to set goals for myself....at first I didn't want to do the rock wall, and then they said set a goal for yourself so I said I'd just go half way.

[Sam]: And when that happened...what did the people around you do?



[Aaron]: They were like ‘yeah! Way to go Aaron and stuff’.

[Sam]: Cheering you on?

[Aaron]: Yeah.

[Sam]: How did that feel?

[Aaron]: It was good. [3r-C8AC-1]

### *Thoughtfulness*

There were two subthemes that emerged in the area of thoughtfulness: 1) confidentiality, and 2) encouragement.

*Confidentiality.* Sharing confidential information required a perception of trust among group members. Camper’s ability to maintain confidentiality was reported as a norm that allowed a camper to open up and discover the importance of transferring this trust into the home environment.

[Kat]: We...when we did the group sessions we had to promise not to tell anybody what was happening, and that made me feel safer, and then when we started talking about it I realized I wanted to talk about it and I talked about it with my friends here. And they wouldn’t tell anybody if I asked them not to tell anybody, so then I decided to tell my friends at home because I saw how supportive they were here, and they were like the same, and they wouldn’t tell anybody....[3-C2AC-2]

While sitting in on an initial group session, the campers were allowed to share how they perceived or would like for the group sessions to be conducted. The Las Vegas seemed to be operative at camp: “What is said in group stays in group.” Campers were

welcome to have follow-up conversations with each another, but were not to share others stories outside of group. This seemed to be the foundation of trust building at camp.

*Encouragement.* The cheerful encouragement and recognition that one gets from others was an example of thoughtfulness. Campers also reported that the CITs were instrumental in providing encouragement. Campers recognized that CIT's wished to give something back to others who were now going through their prior experience with cancer. For example, Aaron noted: "Because they knew how it was when they were a camper, and they want to do as much as they can I guess." [3r-C8AC]

The experience of confidentiality at camp and the willingness of other campers to share their experiences had direct impacts on campers reporting newly found abilities to trust, and communicate feelings at home. Whether perceived instrumental support resulted in a buffering or main effect, in each instance there appeared to be a lessening of some stress or burden for the appreciative camper.

### **Social Comparison**

Meltzer's (2003) study demonstrated that through the mechanism of social comparison, campers reported feeling more similar to camp peers than non-camp peers. They also reported and improved psychosocial outcomes, although the study stopped short of identifying what designed or natural factors led campers to the improved perceptions (e.g., social structures and processes naturally occurring within a camp setting).

Interview coding revealed 23 instances in which campers suggested perceiving others at camp to be more similar to them than friends at home. There were 10 instances

that suggested the campers perceived some improved psychosocial outcome from the being with similar others at camp. Eight of the 23 involved being able to be empathetic; 5 involved able to belong; 4 involved being to relate; 5 involved sibling club categories.

Analysis of the interview data suggested that the mechanism of social comparison had two themes: 1) sense of belonging and (2) being in an empathic environment of similar others. How the campers described their perceptions of having a sense of belonging and an empathic environment at camp appeared to understand the designed or natural factors that led campers to their improved perceptions of feeling more similar to camp peers and improved psychosocial outcomes.

#### *A Sense of Belonging*

Sense of belonging derived from the campers' perceptions that they all come to camp having experienced similar circumstances. As such, campers perceived that they benefited from being in the presence of similar others or people in common. Two subthemes emerged: 1) a sibling club, and 2) an ability to relate or belong.

*Sibling Club.* The concept of a sibling club emerged metaphorically from the commonality that campers shared with each other. Club membership was a consequence of campers having lived with cancer in their households, and the opportunity to participate in a camp experience surrounded by similar others, supportive adults, special attention, and an opportunity to just be a kid. By belonging to this club, campers were able to find solace in the knowledge that they were not alone in their experiences. This sense of universality was the impetus for a genuinely empathic environment.

Universality occurs when a camper perceives that other members share similar feelings

or problems (Yalom, 1995). For returning campers, membership in the club was renewed annually. The concept of social comparison was made manifest, very early on the first day of observations in an interaction with a Peaceable Kingdom staff supervisor.

*[Candy, PK staff]*. She shared a story about last week's camp that had kids with muscle dysfunction disorders. A girl said to her that "I live at my home place 51 weeks out of the year, but I am here at my home 1 week of the year." This story seemed to cause a teary eyed emotion for the counselor. She went on to share that during the camp session for children under five, there were parents who for the first time saw their kids doing something athletic. They saw kids swimming with others like them and began to see what was possible for their child's life in the future. She further recalled seeing a girl from last week's camp that was self-conscious and was not comfortable in a bathing suit because of bruises and scars on their legs. That changed when she became aware that she was around other kids like her. [5-OBS1 10:30 Day 1]

This story is indicative of how CGD had become a special place and an important part of the developmental growth process for returning campers.

There were four instances in which campers reported having a sibling that suffered from cancer as the basis of their perception of what makes campers more similar and the basis for campers being able to relate to each other. For example, in one instance, Selena defined cancer as the commonality between campers; "Well we've all had a brother or sister that passed away and I don't think it really matters what kind of cancer they had, I mean it's still the same thing, it is still cancer." [5qr-C7AC-2]

Campers perceived that other children at camp knew how to treat people that had cancer in their families because they had experienced similar circumstances and were able to empathize. Moreover, those that return to camp remembered being bewildered by the experience of cancer and CGD was where the process of adapting began through the supportive actions and stories shared by similar others at camp. For example,

Tab]: Um, like the people here? They're like very supportive and cheer you on, and stuff. If you don't wanna do it they'll kind of like push you to do it, but not really push you. And it's like, you wanna do it, or you don't have to do it, and they're nice and stuff. Um, a lot of people here are very supportive and they know how to treat a person, like a person whose brother or sisters has cancer and they know how it feels so they're like you in a same way. [5-C6AC]

*An Ability to Relate or Belong.* Campers perceived that they benefited from being around people with whom they had experiences in common. Campers reported being able to relate to campers on a level that made them feel comfortable which allowed them to express their feelings, and in turn led them to bond with other campers. At CGD, campers experienced intense closeness with the other campers over the 3 1/2 days camp period. Campers shared cabins and eating facilities, participated in trust and team building activities, recreated together, watched movies, and took time out for catharsis in the daily sessions. Being in close quarters provided the conditions for close bonding and a sense of relatedness. Jim shared some of the benefits of living in close quarters with friends at camp:

[Sam]: Does your interactions in the cabin with the other campers make a difference at camp?

[Jim]: Yes.

[Sam]: How so?

[Jim]: It's just more time to be with your friends, instead of going off and not doing anything, sitting in your bed and not hanging out with the other guys. [6-C5AC]

*Being in an Empathic Environment of Similar Others*

Campers perceived that an empathic environment derived from experiencing the company of others who knew how they felt and genuinely understood them. Campers were in a safe and supportive environment where they were able to seek and receive affirmation from supportive others. Supportive others included other campers, social workers, volunteer counselors, CIT's, and PK staff. Perceptions of encouragement were consistently expressed by campers. Campers arrived at camp and learned through intentional processes that there were commonalities among campers. The process started by the camp only serving siblings of children with cancer, which provided entry and re-entry into the sibling club. Moreover, group sessions afforded an opportunity for campers to learn more about the common experiences shared with other campers. Campers that came in thinking, "I'm not okay," begin to develop coping skills by being in the presence of similar others that appeared to be overcoming their own circumstances. For example, the campers were afforded the opportunity to function in a recreational setting filled with supportive others, and for at a few days, it was okay to allow the focus of attention to be about the well sibling camper. The camp experience was about campers experiencing being the center of attention without taking attention away from others or yielding attention to others. A sense of commonality allowed campers to experience that they were not alone in their circumstances and thus they were

able to develop compassion for others involved in similar experiences. Campers gained personal strength in seeing how others became able to demonstrate their ability to be okay. As such, campers with deficit thinking began to take on a more positive level and they began to see that “if you’re okay, then I’m okay.”

### **Appraisal Support**

There were 51 instances of appraisal support that emerged from interviews with campers; 27 were instances of affirmation 24 were instances of need for approval; 23 were instances of similar others; 21 were instances of accurate appraisal; and 8 were instances of reported decreases in fear. In examining the response data, there were three primary themes emerged concerning how campers perceived appraisal support at camp: 1) able to relate, 2) empathic environment, and 3) safe and supportive environment.

#### *Able to Relate*

The first subtheme involved camper’s reporting being able to relate better to other campers compared to friends at home. Campers perceived that because of having shared similar experiences, other campers have a better understanding of how each other felt. Having a sibling with cancer somehow placed the campers into a special club of empathetic understanding where campers shared similar feelings, thoughts about cancer, and interests in making friends. Because campers knew what each other had gone through, they felt more comfortable talking to other campers about their feelings and perceived that they were able to receive credible advice from others at camp. Campers reported that it was refreshing to find similar others at camp. Two quotes depicting a relational commonality in this special club follow:

[Sam]: So what did you learn being at camp?

[Jim]: I learned, I thought that there weren't many kids like me but it turns out that there really are. [4r-C5AC]

[Sam]: When you say they're going through something you're going through, how is that different from friends outside of camp?

[Angel]: Because they don't understand the feeling, because they don't have a sibling that has cancer or leukemia or anything.

[Sam]: So that makes a difference for you then here that these kids have gone through something similar?

[Angel]: Yeah.

[Sam]: And are you able to talk to them in ways different?

[Angel]: Yes. (4q-C4AC-6)

### *Empathic Environment*

Campers come to camp seeking affirmation and seeking to affirm others. At CGD all campers received special attention. Special attention was an expected norm from adults at camp. This norm was encouraged in group sessions and during activities. Campers were encouraged to focus on themselves as a special person deserving of special attention. The campers tended to reside in households that were scheduled around the needs of the ill sibling. Often there were restrictions placed on the well siblings activities and kids were often distinguished as either the ill sibling (special child) or well sibling (other child). At times, the identity of the well sibling becomes defined by their relations with the ill sibling. At camp, campers were encouraged to



think more about themselves, treat and enjoy themselves, and let their camp experience be about them. As a result, kids became open to receiving affirmation from others at camp and became concerned about providing affirmation. This point is illustrated through the interview dialogue with Tabithia;

Tabithia...People like help me by, they ask me how I'm doing and stuff, and they pretty much take care of me and make the kids here the center attention. So everybody gets equal attention.

[Sam]: How do you like being the center attention?

[Tabithia]: I like to know what people think about me and I like to know that people think about others too. [4q-C6AC]

#### *Being in a Safe and Supportive Environment*

The second appraisal support theme involved the perception of being in a safe and supportive environment where others at camp are empathic. Interview data suggested that campers report learning that it is good to talk to someone about their feelings. However, campers perceived that it is better if the other person knows how you feel. Campers perceived that others at camp were able to provide real empathy because of having a shared experience to draw from. As such, being in the presence of similar others facilitated the ability of campers to share experiences and express feelings with others at camp. Campers perceived that others at camp were nice and not mean which equated to feeling more comfortable expressing feelings.

Campers perceived themselves to be encouraged by the supportive actions of others which also provided affirmation. Campers appeared to describe a safe and

supportive environment where other campers did not ridicule others and a camp norm of confidentiality was maintained. Campers credited instances of encouragement and confidentiality for helping to decrease fear and increase their ability to express their feelings. One camper suggested that campers were the center of attention and equal attention was provided to all campers while at camp. The following are two examples of campers explaining their ability to talk at camp:

[Angel]: Sometimes when you have, like friends, that have, or need to talk about it, you can talk to them and they will understand because they are going through what you're going through, and that's how I feel comfortable. [4r-C4AC-1]

[Sam]: What happened at camp that made you able to talk about it?

Moreover, these observations by Kat explain her importance placed on confidentiality at camp:

[Kat]: We...when we did the group sessions we had to promise not to tell anybody what was happening, and that made me feel safer, and then when we started talking about it I realized I wanted to talk about it and I talked about it with my friends here. (3-C2AC-2)

Moreover, campers that were slow to join in on this unique special attention were inevitably wooed by the encouraging emotional support and affirmation that resulted from just participating rather than an emphasis on winning.

Overall the interviews with campers and observations conducted at camp provided a better understanding of what aspects of the camp experience led campers to report that they have received social support at camp. Results discussed in this section suggest that campers perceived emotional, informational, instrumental, and appraisal

support at camp. In addition, it appeared that social comparison was present as campers perceived themselves to be in the presence of similar others. Results from this section will be discussed in Chapter V along with implications for research and practice

## CHAPTER V

### SUMMARY, DISCUSSION, AND IMPLICATIONS

#### Summary

While previous studies have demonstrated that social support and social comparison occur at camps for siblings of children with cancer (Meltzer, 2003; Murray, 2001; Roberts, 1988; Williams (1997), these studies have not fully explored the characteristics of the camp experience that produce these outcomes. Thus, the purpose of this study was to explore how campers who were siblings of children with cancer perceived social support at camp and to conduct an interpretive analysis of what aspects of the camp experience lead campers to feel supported. The current study was guided by House's (1981) framework for research on structures and processes of social relationships. Results from the interpretive analysis of selected camper's interview transcripts and participant observations notes led to the identification of the following themes and subthemes.

Campers indicated that they received emotional support at camp as a result of: 1) people at camp being encouraging; 2) people being nice; 3) camp provides an empathic support system; and 4) campers are able to express feelings at camp. Camp provided campers with a perception of emotive support through active encouragement from others. This encouragement was embedded through a social norm of people at camp being expected to be nice. Campers perceived they were able to both express and explain feelings at camp to supportive others who offered empathic support. Empathy was perceived as genuine from similar others that were able to relate to campers lived

experiences. The camp creates structured opportunities for group processing to allow campers to experience a safe and supportive environment, a sense of commonality, and opportunities to express their emotions openly without fear of being ridiculed. Thus, emotional support at camp for these siblings of children with cancer provided the buffering that House (1988) suggested is facilitative of psychological and behavioral processes of coping and adaptation in the face of stress. Indeed, campers did report an ability to express their feelings and that it was an important adaptive coping skill.

The process of emotional support appears to occur through an affective context. Not only did campers report being able to express feelings, but also perceived being able to explain feelings at camp. The ability to explain feelings suggested the development of camper's self-confidence and supports House's (1988) views on psychological mechanisms where he suggests that social relationships may alter the perception or cognition of the world in general, or of potentially stressful events and situations in particular. Having opportunities to express feelings in camp can serve as a coping skill that has the possibility of transference to the home environment.

Informational support also occurred at camp. However, it did not appear to be as prominent as the other elements of social support. Campers reported informational support to be the result of receiving: 1) clarification about the ill sibling's condition; and 2) information which provided an adaptive skill for the camper. These findings support House's (1981) discussion of informational support as not being helpful in and of itself, but rather serving to help people to help themselves.

Instrumental support was perceived to occur at camp as a result of others being: 1) helpful; and 2) thoughtful; and resulted in camper's perceiving that they had gained 3) adaptive coping skills. Being helpful involved being caring, supportive, ready to lend a hand, or obliging, while thoughtfulness involved being considerate, unselfish, or attentive. How campers generalized helpfulness was by reporting that they were able to relate to others at camp. Being able to relate was associated with receiving helpful advice and learning from other campers. These perceptions appear to be consistent with receiving supportive and caring assistance from others. Generalized thoughtfulness was characterized by feelings of being comfortable at camp because other campers treated expressions of feeling and information as confidential. Moreover, those other campers were willing to share personal information and personal items, in addition to being nice. These perceptions appear to be consistent with receiving considerate and unselfish support.

Appraisal support is a process of youth going through a self-evaluation/comparison and affirmations that one's interpretations of self are in fact appropriate. The outcome of appraisal is helping to decrease fears and misconceptions about one's condition. Through the process of appraisal, children are able to reaffirm that they are important and cared for, and that they matter as individuals. Through universality (Yalom, 1995), camp afforded an opportunity for campers to learn from the experience of others and learn that they are not the only ones enduring their situation. The literature suggests that appraisal support may satisfy a need for approval, accurate appraisal of the self, generally leaving campers more satisfied with themselves and their

circumstances (House, 1981). Campers seemed to express that there were three ways in which they perceived appraisal support: 1) having an ability to relate to others at camp; 2) being in an empathic environment; and 3) camp providing a safe and supportive environment.

Social comparison was operative at camp and was perceived to be the result of: 1) sense of belonging and (2) being in an empathic environment of similar others. Two subthemes emerged to describe campers perceptions of having a sense of belong: 1) A sibling club and 2) An ability to relate or belong. The sibling club is emerged metaphorically from the commonality that campers share with each other. Club membership was a consequence of having lived with cancer in their household's affords the opportunity to participate in a camp experience surrounded by similar others, supportive adults, special attention, and an opportunity to just be a kid.

Campers report being able to relate to campers on a level that makes them feel comfortable which allows them express their feelings. This ability to express feelings creates a sense of relatedness that leads to bonding among campers. However, in the grand scheme of how campers are connected, it was acknowledged by campers that the commonality that exists between them is cancer.

Campers also perceived being in an empathic environment at camp. It appears that campers come to a safe and supportive environment where they perceive being able to seek and receive affirmation from supportive similar others. Drawing on camper's sense of commonality allows campers to experience a perception of universality or that other members share similar feelings or problems (Yalom, 1995). Through these

processes, campers came to appreciate that they were in an environment of similar others that were bonded by similar experiences. Things that may have seemed awkward at home were normalized through hearing self disclosures in group sessions.

Campers gain personal strength in seeing how other campers become able to demonstrate their ability to be okay. “If you’re okay, then I’m okay,” is a statement of processes at camp that represent the mechanism of social comparison where campers look to others for an image of themselves because they do not have an objective standard by which to measure or compare at home. Social comparison theory suggests that as humans, we have an innate drive to evaluate our emotions and abilities. The finding of campers reporting being in the presence of similar others supports Meltzer’s (2003) study which demonstrated that through the mechanism of social comparison, campers reported feeling more similar to camp peers than non-camp peers. It further appears that being in an empathic environment where campers perceive a sense of belonging and a sense of voice in the presence of similar others leads to the development of coping skill competencies. Campers reported learning that it is good to talk with others when feeling troubled and in some cases begin to enjoy talking with others at camp.

Camper’s report distinguishing non-camp peers as being people who tend to feel sorry for them but camp peers understand their feelings and experience. A tacit explanation suggest that campers perceive that most non-camp peers have no perceptible visual evidence of these camper’s experience of isolation, home restrictions, parenting relief, disruption of social life, fears, depression, or any other deleterious internal impact that having a sibling with cancer is causing. Campers report improved psychosocial



outcomes as a result of a learned awareness that it is good to talk with somebody if you need to talk. In particular they learn that it feels good to talk to someone who knows what you feel or knows how to treat people with an ill sibling. Findings support House (1988) assertion that people will feel better psychologically when their basic human needs for relationships are fulfilled. Moreover, this study finding may further support House suggestion that stress arousal may increase when access to social relationships are threatened and stress arousal is likely to be reduced when these relationships are intact.

A finding of interest was that campers who commented on a need for approval also noted receiving affirmation. However, comments regarding affirmation did not seem linked to comments about similar others. This finding suggests that campers who have a need for approval are likely to seek out affirmative feedback whether at a camp with similar others are outside camp among non-similar peers. Also, the lack of connection, drawn from the data, between need for approval and similar others suggests that the need for approval may likely be activated prior to the camp experience. Moreover, the need for approval may be tied to a more natural need for sense of belonging or relatedness to others. This may indicate that a camper's need for approval or affirmation may be driven by unstable private life so campers seek an appraisal.

Festinger (1954) has indicated that when our evaluation of ourselves in private is unstable, then given an opportunity to compare ourselves with others, the comparison would have a considerable impact on the evaluation of self. This may be one explanation for why campers comparing themselves against non-similar others at home can have deleterious impacts. Festinger (1954) further suggested that to the extent an opportunity

for self-evaluation does not exist, the drive for self-evaluation becomes a force that acts upon persons to belong to groups and to associate with others. Consequently, CGD, by intentional design, happens to be where similar others are placed together in close setting and are able to achieve comparison to the lived experiences of other participants.

Because appraisals were perceived to be more accurate at camp, campers reported feeling more comfortable around other campers, a psychological benefit.

As such, campers perceived that when socially comparing at camp, they learned that through an appraisal process they received positive affirmation, accurate appraisals and benefited from being in the presence of similar others or people in common.

While positive testaments to social support have been the focus of this thesis, there were statements and observations which suggested that a few campers may not have initially felt social support at camp. However, after being at camp a while those campers began to demonstrate being socially supported. Although camp allowed participation-by-choice, it was hard for campers to resist participation as the affirmation of others witnessed by non-participating campers was too enticing to pass up. As demonstrated by the following quote, the supportive encouragement remained the same whether campers partially or fully participated: [Ro]: Like, ‘you can do it, you can do it climb!’ but if you don’t climb it and you go back down, they’ll still congratulate you. [1-C4AC-1]

## Discussion

The interviews and observations confirmed that social support was occurring at camp. They also suggested two other themes that were significant to understanding the mechanisms that led campers to perceive that they were being supported. These included designed and natural aspects of camp that appeared to influence camper's perceptions of social support. A discussion follows.

### *People Are Nice*

CGD affords an opportunity for siblings of children with cancer to be away from the normal conditions of a home environment. Being able to go to camp is important since it is the siblings of children with cancer who are the most emotionally disregarded and distressed of all family members as a result of their sibling having cancer (LaGreca 1992; Martinson, I.M, et al., 1990). Therefore, it is not surprising that campers respond positively to a supportive environment. When campers were asked to describe supportive behaviors, it became apparent that campers had already thought about this question prior to sitting down for an interview. An overarching perception by campers was that people at camp were nice. In addition, an observed presence of universality and a cycle of reciprocity at camp helped elucidate an explanation of the nice phenomenon.

At camp, norms and values were established in group sessions and carried out throughout the camp experience. Campers were guided through a process of establishing a means of communication and conduct at camp during the very first group session. Campers agreed to: respect others; not ridicule others; adhere to confidentiality; honor each other's right to participate by choice or right to pass. These norms served to self-

regulate camper's behavior. As these norms were honored, campers reported perceiving others at camp as being helpful; thoughtful; empathetic; and nicer than friends at home. As a result, these norms and perception lead campers to equate that people at camp are nice.

There seemed to be a willingness to expect the good in all campers and have the patience to understand that campers come to camp with similar issues occurring at home. Previous campers had not forgotten how they felt the first time they came to camp and openly sought to make the experience of others pleasant. Appraisal support suggests that people have a need for approval from others and people tend to socially compare when they we do not have an accurate appraisal of themselves. A part of seeking approval at camp was experiencing the perception that one has availed themselves to others for support as they have been shown support in the past. This equated to a concern for the wellbeing of others at camp. At camp, there was an expectation of nice, and meanness did not fit nor seem to survive within this norm. This conclusion is illustrated by Tabithia willingness to seek friendship and overcome the perception of mean from a camper that exuded a cold demeanor: "I met Selena, and she's very nice. And I thought she was gonna' be mean, 'cause I saw her and she looked like kind of a mean person but once you get to meet her and talk to her she's very nice." [4r-C6AC] Observations at camp suggested that this desire to seek friendships grew out of the "nice" norm that occurred at camp and the establishment of commonality early in the group sessions.

### *Universality*

Campers appeared connected at camp by a common set of experiences at home (e.g. restrictive activity, excessive hand washing). These connections developed into a culture or special club that finds its existence in the common knowledge of all campers having a right to belong to this club as a result of their having a sibling with cancer. When not at camp, the campers were subject to the social norms at home, school, church, etc.. Those norms served to restrict behaviors as well as guide acceptance within the particular contextual setting. The norms govern the ways they come together and negotiate acceptable interactions. When campers come to camp, they have to negotiate a different set of norms, values, and beliefs.

Kids at camp reported feeling as though friends at home showed concern for their welfare; however the concern felt more like sympathy or was perceived as feeling sorry for them. In addition, for many campers, normal interactions within their social networks at home were restricted possibly creating a perception for campers of no longer being normal. Suddenly, kids come to camp with a renewed opportunity to create a set of norms in a way that they can think of themselves as being normal. Thus, camp provided an opportunity to reconnect with the norms, values and beliefs that may have existed in their home life prior to the ill sibling's diagnosis. It could be that camp provided training for how to deal with a new set of norms allowing kids to discover that it is normal to deal with a different set of norms as a part of what happens when someone gets sick. Parents were likely to have experienced the processes associated with dealing with unplanned events, changes, loss of employment, illness, and death. While there may be

societal norms associated with how to cope with sudden disruptions in lifestyle, there is not a manual of preparation beyond one's own experiences. As campers came to camp, they participated in an experiential opportunity to build a community of similar others. The community was based on creating norms, values and beliefs associated with having a safe and supportive environment, confidentiality, and respect for others, a right to pass, and an expectation of people being nice. Counselors worked with campers to develop these norms and campers moved from operating under norms that appeared abnormal to those that helped them feel normal again. As the campers functioned within these norms, campers found themselves learning to receive emotional support from empathetic others as well as being able to give support to others. Campers went from feeling like outsiders, isolated from others experiencing similar circumstances, to having an opportunity to communicate with other kids with similar home-based experiences at home. How they communicated with each other was with kindness and tolerance for others who have emotional moments. This was illustrated when Aaron didn't experience the completion of the Zip-line high rope challenge as he had anticipated and he began to distance himself from the group during the follow up team building challenge activity. The group went on without him while Aaron sulked in isolation. Nevertheless, when all of the campers had completed the activity except Aaron, the attentive social workers asked the group if the challenge activity was indeed finished if all team members had not completed the team building task. At this point, the group began to focus on Aaron and began to provide supportive encouragement.

Observing Aaron's interactions within his group was quite powerful in furthering the expectation of people being supportive. Aaron waited for people to be supportive and when the opportunity presented itself, the campers did not hesitate to show tolerance and provide supportive encouragement. Moreover, they moved on without animosity toward Aaron, which allowed him to rejoin the group without any ridicule over him having had his emotional moment. Campers seemed to know that they all had strong emotions and that camp was the place to release those emotions with a full expectation that other campers would be understanding or remain nice. There were no statements or gestures made toward Aaron related to why he had chosen to go into isolation. The focus was on treating him as "special" for being a part of the team and contributing to the achievement of the team goal. The campers did not allow Aaron's self-pity to control their enjoyment of camp or their activity participation. This moment demonstrated the ownership by campers of the camp's goal of helping kids to focus on them, that they were deserving of special attention and that they should not allow ill sibling's condition to restrict their own right to participation. In addition, at camp kids could express genuine feeling by way of a silent vote to move on. The other kids were not mean, nor were they perceived to be by Aaron. Yet, Aaron was able to show resilience by being able to move from his repressed involvement to becoming an essential part of the team in the next team challenge activity. Being alone at camp occurred only by choice as the camp processes valued a sense of belonging for all campers.

The researcher's observations suggest that camper's discomfort with expressing feelings at home were tied to not wanting to receive what they perceived as sympathy

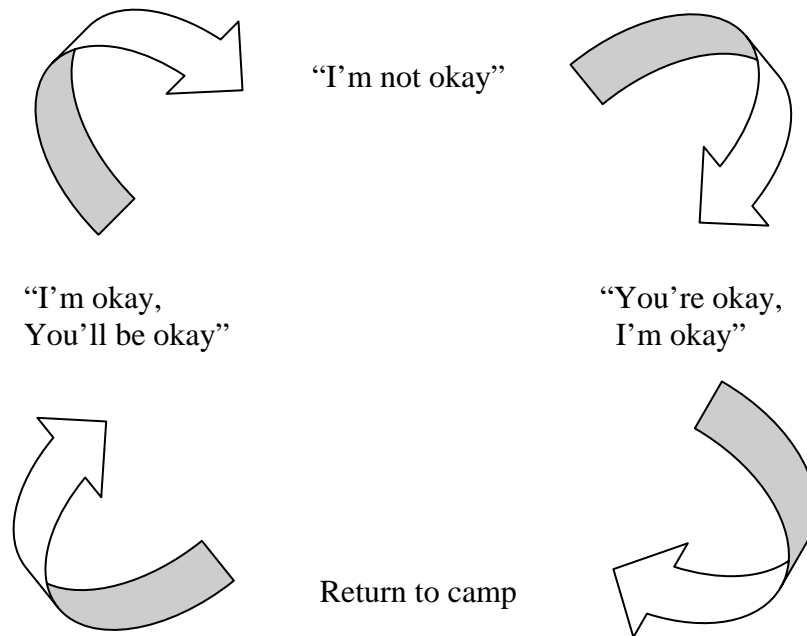
from others at home. Being empathic is the practice of placing ourselves in the position of others, and somehow feels what they are feeling without having to share our own comparable experience. Therefore, we place ourselves in the mental position of conceptualizing the experience of others without demeaning their lived experience through trying to make sense of it through a related experience. At camp, campers could relate because of their shared experience

### *Cycle of Reciprocity*

When campers lost the ability to function under conditions perceived as normal around the home, they became vulnerable to the belief that they are somehow different. Upon arriving at camp, campers may bring their apprehension about how to conduct oneself away from what, for some, has become a restrictive home environment. The camp experience placed campers in the presence of similar others who could bring shared experiences that could help them to begin to normalize their circumstances. This process helped campers rediscover a sense of normalcy and the ability to function more adaptively given the situation at home. In group sessions, campers learned of other's similar experiences and empathically sought to listen, share experiences, and help others feel if "I'm okay, and then you'll be okay." Over time, campers progressed from "I'm not okay to "you're okay, I'm okay" to "I'm okay, you'll be okay." As campers enjoyed the CGD experience of having supportive others, they adopted the inter-subjective norm of wanting to give back. As campers returned annually, or later as CITs, campers took on the stance of being the reciprocator, or "I'm okay, you'll be okay." The presence of returning campers was what provided the essence of hope and the continuation of the



tradition of norms that made CGD a safe and supportive environment where people are perceived as nice. A conceptual explanation is provided in figure 4.



*Figure 4: Cycle of Reciprocity.*

Thus, at camp there appeared to be a cycle of reciprocity. CGD seemed to promote a camp norm that expected campers to “treat others like you have been treated by others.” Reciprocity suggests a mutual exchange of favors or resources. At CGD, there is no mutual exchange expected from helping others to have a good experience at camp. On the contrary, it is the opportunity to reciprocate, as modeled by prior campers and counselors, which made the cycle a norm that operated as one of the mechanisms for the friendship bonding that occurred at camp. Thus, there appears to be a common theme

among prior campers at camp to want to help others experience what they have enjoyed at camp.

### *Efficacy of Camp Grey Dove Intervention*

CGD provided experienced social workers who were proficient at facilitating group sessions, undertaking crisis interventions and providing a holistic care priority for all campers. CITs brought a high level of commitment to providing an experience for campers that equated or exceeded their prior experiences as campers. Although social support was not directly stated as a goal of camp, it was implied in the intentionality of camp and the desired outcomes of wanting to decrease feelings of isolation; increase camper's abilities to express emotions; increase confidence; and provide increased opportunities for interaction between the campers.

CGD is part of an overall strategy to provide support services for families of children with special needs. The goals of CGD were to:

- Provide youth with a fun experience while at camp.
- Help youth make meaningful connections with other siblings of children with cancer.
- Help youth deal with difficult issues while feeling safe in a supportive environment.

When campers were asked what they liked most about camp, they generally reported some form of recreation activity in which they had participated. The fact that campers indicated that if possible camp should be longer provided additional evidence that campers had a positive experience at camp. Providing a fun experience was critical

to providing an environment where siblings can take a break from any restrictions on activity involvements they might have arising from their own or parents' efforts to provide care for ill siblings.

It appears that the campers are being positively impacted by social workers (group sessions); Peaceable Kingdom staff (challenge activities); camp counselors (cabin interactions); counselors in training (e.g., piggy back rides and play modeling), and peers (social interactions). Attentive support provided by social workers, supportive encouragement from the Peaceable Kingdom staff and CITs, and late night dialogue in cabins among counselors and campers combined to create a positive social interaction experience. When talking to CITs, it was clear that they attributed development of their coping skills to their experiences at camp. Interviews with campers suggested that for some it may have been too soon for them to make a connection between the camp experience and coping skills at home. Thus, it would appear that camp created opportunities for some child to be resilient while facing difficulties associated with being a sibling of a child with cancer.

The counselors did a good job of insuring success for each camper who chose to participate in the challenge activities. Camper's willingness to participate by choice, even when experiencing anxiety, appeared connected to the encouragement they received from the counselors and other campers during the challenge activities. A sense of commonality was facilitated in group sessions which were used to support team building opportunities during the group challenge activities. This process seemed to build confidence and trust among campers in an emotionally and physically safe

environment. Some campers reported learning adaptive coping skills while participating in challenge activities. Interviews with campers suggested that for some it may be too soon for them to make a connection between the camp experience and coping skills at home. Nevertheless, it would appear that camp created opportunities for campers to develop resiliency skills while facing difficulties associated with being a sibling of a child with cancer.

Overtime campers came to understand that they were among peers that shared common experiences and were willing to adhere to camp norms of: confidentiality; respect for others speaking; no teasing; and a right to pass or participate by choice. Overall, it appeared that Camp Grey Dove was providing a quality in camp experience in a safe and supportive environment.

While intentionally designed activities at camp directly facilitated the development of friendships, there were natural aspects of camp that facilitated the development of meaningful relationships. There were unstructured interactions that took place during theatre time; cabin time; and swimming pool and camp fire socials that occurred naturally among campers. Observations and camper interviews suggest that meaningful friendships are deepened during these unstructured social opportunities indicating an importance of free-play and free-choice time.

Social support and social comparison appeared to be important mechanisms for the camp attendees. Children indicated that other children at the camp know what others are going through without necessarily having the pressure of them needing to explain. Thus, it is important that professionals committed to strengthening families, remember to

consider the needs of siblings of ill children to socially interact with similar others. The top five themes that emerged from participant observations to explain how campers perceive social support is occurring at camp included:

1) *Presence of Similar Others*: Campers described feeling real empathy and not having to endure feelings of sympathy, as they often received from friends at home. Parents and campers shared a common perception that camp provided an excellent way for siblings to be in the company of other kids experiencing similar circumstances. Evidence of appraisal support through the mechanism of social support was also observed.

2) *Safe and Supportive Environment*: Campers perceived that camp afforded a safe and supportive environment to express feelings or withhold sharing without being ridiculed. Group sessions supported the campers' right to pass during group sessions. This right was reiterated by staff during challenge initiatives.

3) *People are Nice/ Respect for Others*: Campers uniformly perceived active encouragement from counselors and other campers. Friendship at camp was distinguished from friendship at home by using the descriptive phrase: "kids here are nice." Campers reported having more cordial relationships at camp and a desire to conform to an inter-subjective norm of being "nice" at camp. Observations supported the idea that there was an expectation of being "nice" which permeated the camp environment and was a norm expected of all.

4) *Special Friendship Bonding*: Campers described experiencing bonding through social interactions at camp and living closely with others over its short duration.

Campers uniformly perceived that camp should be extended (3 to 5 days) citing opportunities for extended fun and deeper friendship enjoyment as the prominent reasons. Observations indicated the importance of cabin time as a conduit for deepening friendships after a rigorous camp schedule.

5) *Quality of Staff and Counselors*: Campers reported perceptions of being treated as a special person at camp by camp staff. Campers reported that counselors allowed them to be a kid, free from restrictions and parental responsibilities. Active encouragement, high tolerance, and play modeling were observed. CITs performed play modeling, encouragement, and piggy-back rides that afforded opportunities for emotional support.

Practitioners should consider increasing the likelihood of a camp's program delivering the social support as perceived by campers through intentionality training. In addition, the author encourages practitioners to examine a camp's mission, rules, activities, and training to remove barriers that restrict social support from occurring at camp. Discussions should be held with staff to identify and compare how they perceive support is being provided to campers. Descriptive stories will help increase all staff members "how to be supportive" tool box. Camp should also make relationship-based programming a key element in CIT training. It is important to explain the relational content of social support in helping to enhance attachment to others, purposeful interactions and coping skills, self image, and self confidence.

## **Implications**

### *Implications for Theory*

*The Impact of Camp Structure on Social Support.* At camp, microsocial relationships facilitated the camp experience of social integration (quality of relationships), and multiple social network types (one-on-one, small group, large group, teams, formal and informal groups), both in a highly supportive relational environment. These concepts are depicted in Box A. of Figure 5. The structure of supportive camp environment that makes up the social integration and social networks at CGD included: group process sessions; outdoor adventure challenges; social bonding opportunities; creation of a safe environment; and supportive counselor and staff interactions. Based on the reported interviews and camp observations, it appeared that this type of programming enabled campers to experience social support.

The process of social regulation among campers was health promoting through a self-controlling camp norm of people being nice. The term “nice” is embedded in the camp tradition as repeat campers and CITs reported wanting to give back to others at camp because of the influence of how helpful and thoughtful campers or counselor had been to them previously. When considering the interest in returning to the CGD experience, it appears that the consequences are lasting benefits that result in campers wanting to pass on their positive experiences to others at camp.

Counselor and camp staff did a good job helping campers value their commonality through feeling of universality which helped to regulate camper’s behavior. These concepts of social regulation are shown in Box B of Figure 5.

Observations suggested that counselors are well liked by campers. Experienced social workers (counseling abilities, holistic approach to servicing children) and well trained Peaceable Kingdom staff allowed structured processes to help guide campers through psychosocial breakdowns and the development of adaptive coping skills at camp. Campers were able to articulate their awareness of coping skills learned during activities, group sessions, and personal interactions. Interviews and participant observations confirmed how camper's perceived social support through the elements of emotional, informational and instrumental support. These concept variables are shown as part of the relational content in Box B of Figure 5. It appears that social integration and social networks provided during the camp experience were the inputs that led to the positive outcome benefits of health and well being through relational content of social support provided by CGD. Figure 5 is provided as an updated amended modification of the simplified version of House's (1988) framework on structural processes presented in Chapter I; to help conceptualized the findings in this study.



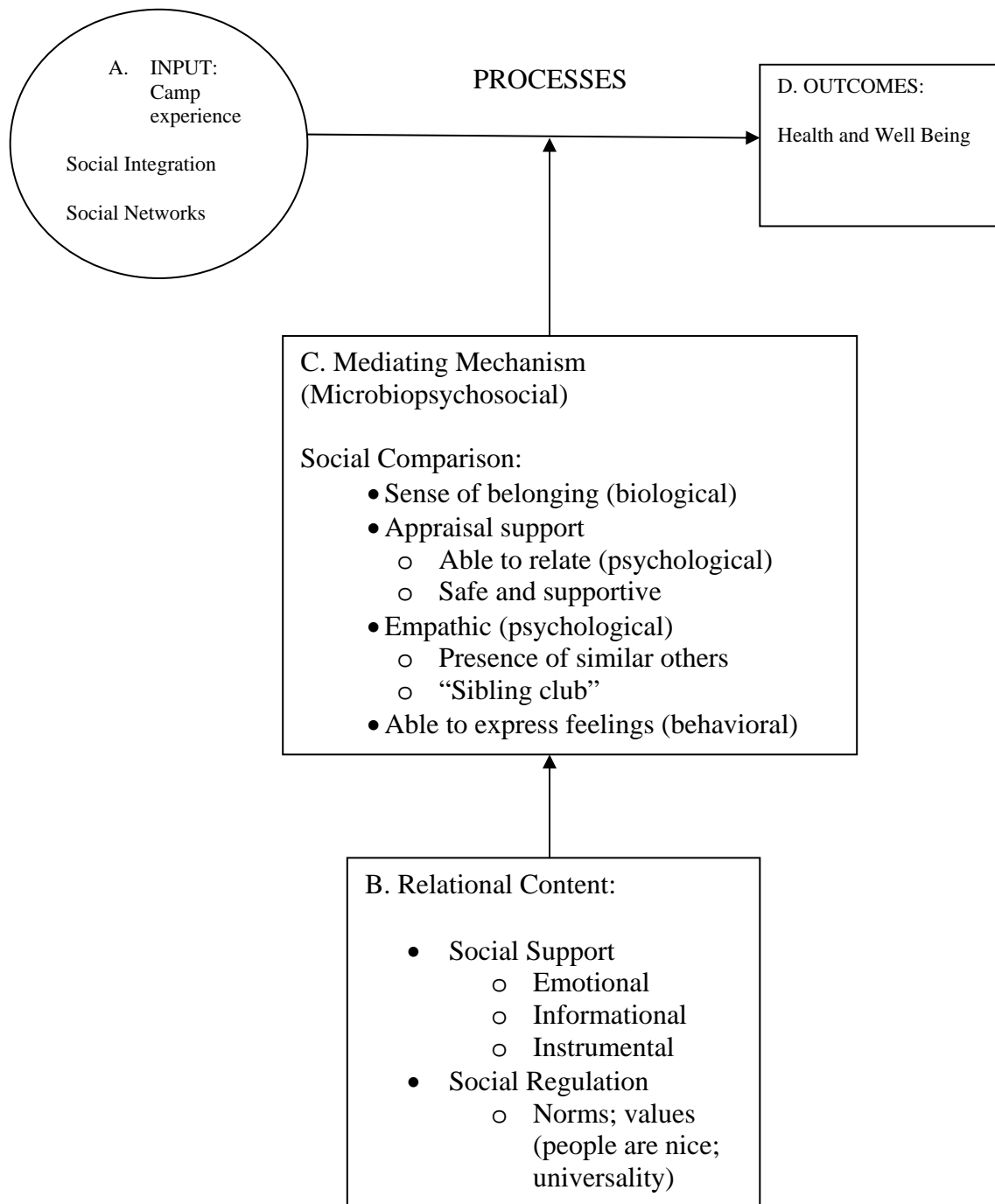


Figure 5: Amended Model.

House (1988) suggested that social relationship networks and supports may have buffering effects through a variety of mechanisms. In his writings, he suggests three mechanisms: a) biological (explain how we seek attachments to others); b) psychological (purposeful interactions with similar or non-threatening others); and c) behavioral (the development of coping skills that serve to protect us against health hazards, like giving up smoking). These mediating mechanism are shown in Box C of Figure 5.

In explaining biological mechanisms, House (1988) reviewed ethological and sociobiological evidence supporting the theory that humans are genetically programmed to seek social interaction and form relationships, perhaps as a defense mechanism or enhanced survival technique. Moreover, studies of both humans and animals suggest that cardiovascular anxiety can be reduced by the mere presence of similar or non-threatening others, especially affectionate physical contact (House, 1988, p. 307).

At camp, campers reported that being in the presence of similar others was a source of support that made them more comfortable, an indication of reduced anxiety that could have a direct effect on improved psychosocial adjustment health (Murray, 2001). For purposes of this study, box D of Figure 5 represented Caldwell and Smith (1998) broader, holistic definition of health in which refers to a state of well-being which encompasses emotional, physical, social and spiritual health. The presence of similar others, who are different than their friends at home, led to the perception of people being nice and able to maintain confidentiality. These perceptions helped camp to be seen as a non-threatening, safe and supportive environment. As a consequence campers were able

to report feeling a sense of belonging at camp and an ability to relate better to people at camp.

House (1988) also discussed psychological mechanisms. When the fulfillment of a basic need for attachment is experienced in social relationships, humans are likely to benefit from having a healthier psyche, for example, by altering their cognitive perceptions of stressful situations (House, 1988, p.307). Cognitive appraisal can help link social stressors to health, and the role of social relationships in moderating such appraisals, has been emphasized in writings by Lazarus and colleagues (Lazarus, 1966; Lazarus, Averill, & Opton, 1974).

At camp, siblings of children with cancer are brought into the presence of similar, non-threatening others, where all campers have in common that they have a sibling who has or had cancer. This equates to campers being provided with a social network of others with similar experiences. Campers find it difficult to generate a subjective comparison for their reported experienced feeling of jealousy, guilt, isolation, anger and other feelings and emotions, often newly felt, at home. As humans we share an innate drive to evaluate our emotions and abilities, and if there is no objective standard by which to compare ourselves, other people become sources of implicit or explicit evaluative information that individuals use to evaluate themselves (House, 1981; Meltzer, 2003). Thus at camp, campers experience close intense contact with other campers over a period of 3 ½ days and are thereby afforded an opportunity to cognitively appraise themselves through contact with other campers who have had similar experiences. In Meltzer (2003) camp study, she reported:

- (a) ...participants reported feeling more similar to camp peers than non-camp peers;
- (b) adolescent participants reported significantly greater social acceptance when comparing themselves to camp peers versus non-camp peers; and
- (c) loneliness was significantly predicted by how different children felt from non-camp peers (those who felt more different reported more loneliness) (p. 7).

The current study's findings appear to support Meltzer's first two findings, but there was insufficient information related to issues of loneliness to draw any conclusions.

According to Totman (1979) psychological health and physical healing depend on purposeful social interactions to support and reaffirm consistency in an individual's values and worldview (Antonovsky, 1987). Observations and camper reports at CGD suggested that intentional planning of group sessions led to a sense of commonality and perceptions of being safe. In addition, as a result of campers being able to openly express their feelings about their experiences with cancer, other attentive campers were empowered to reaffirm that their values and feelings shared universality with others. In turn, these reaffirmations helped reduce anxiety about feelings of not being normal or somehow falling short of normalcy, as perceived by others outside of camp. Therefore, the experience of campers at Camp Grey Dove appears to support House's assertion that when basic human need for social attachment or relationships are fulfilled, positive physiological consequences can occur, resulting in a lessening of stress or anxiety and improved health.

House also argued that behavioral mechanisms are at work in facilitating individual or collective behaviors that are promotive of health. These adaptive coping behavior mechanisms, can serve as protective factors in the presence of stress or health compromising influences. At camp, trust, courage, and team building activities are purposely designed as a part of the CGD adventure challenge experiences. In all activities, both campers and camp staff were “encouraging” and facilitative. Campers reported learning adaptive coping skills and were able to suggest how coping skills would have transference in to their home life. A long term goal of camp was to enable campers to have a positive learning experience in a highly supportive environment and, as a consequence to be able to utilize the experience of social support as a buffer in the presence of stress when back in an environment of non-similar others. However, evidence in the literature of the long term impacts of camp attendance is weak, though there certainly appear to be impacts, especially for repeat campers. Findings of proximal outcomes such as increased adaptive coping skills may lend support for the possibility of more distal impact evidence over time supporting Berkman and Breslow (1983) argument that adaptive coping behaviors are a major mechanism linking social support to health.

In summary, the findings from this study appear support social comparison as a description of the biological, psychological and behavioral mechanisms noted by House (1988). Festinger (1954) has suggested that when our evaluation of ourselves in private is unstable, then given an opportunity to compare ourselves with others, the comparison would have a considerable impact on the self-evaluation. Festinger (1954) further

suggested that to the extent an opportunity for self-evaluation does not exist, the desire for self-evaluation becomes a force that may drive individuals to associate with others in pairs or in groups. Festinger's ideas were supported by the creation of opportunities to belong for children at CGD.

Meltzer explains that as humans we have an innate desire to compare. Camp brings participants in contact with similar others, thus meeting a biological need for attachment. This affords an opportunity for accurate appraisal as reported by campers and affirms a sense of belonging. This sense of belonging could be labeled as creation of a "Sibling Club." Having an awareness of being around similar others, campers participated in purposeful interactions where they were afforded opportunities to socially compare and determine that, since others are okay, "I'm okay" or "I'll be okay." By meeting of the need to belong through social comparison processes, campers learned that they were not alone in their experiences, i.e., feelings of universality. As campers became more comfortable, active participation lead to campers being able to articulate a cognitive awareness of learned adaptive skills (behavioral).

As campers processed their newly found experience of universality, positive physiological consequences emerged which led to reductions of stress at camp as evidenced by campers reporting feeling supported; being able to express feeling; being able to relate to others; increased confidence; being able to avoid depression; being happy; and having fun. Therefore, Meltzer's claim that social comparison is one mechanism that leads campers to perceive social support appears to have been supported

by the current study. Further studies should investigate social comparison in other specialty camp settings.

The attempt at conceptualizing the CGD experience of social support was guided by House's seminal attempt to outline how mechanisms are contributing to the processes that lead campers to perceive social support. The significance of this study is that while social comparison has only recently been introduced in the body of literature addressing the siblings of children with cancer, this appears to be the first known attempt to develop a linkage between social support at a camp serving siblings of children with cancer as experienced through the House (1988) structures and processes theoretical framework.

This study supports House's theory of how structures and process of social relationships work in relation to good health can be applied to a camp setting. There has been a growth in psychosocial support programs, including camping experiences, designed to assist families through childhood cancer. The chances for success with achievement of desired outcome benefits at camp are enhanced when a theory of explanation logically connects camp inputs to outcomes. The significance of this study is that it provides an explanation of how the structures and process of social relationships in a camp setting interact to improve a camper's perceptions of supported.

#### *Implications for Practice*

This study strengthens arguments for more camps like CGD. Intentionally designed camps have the ability to impact a broad range of attitudes and behaviors. This study supports other research that suggests that intentionality matters. In addition, camps seeking to impact campers' perceptions of social support through the mechanism

of social comparison may wish to consider increasing the length of the camp experience to determine if additional or more in depth impacts are possible.

Social support appeared to be an important mechanism for the children attending camp. Children indicated that other children at the camp know what each other are going through without necessarily having the pressure of needing to explain. Thus, it is important that stakeholders committed to strengthening families remember to consider the needs of siblings of ill children to socially interact with similar others. In addition, findings from this study may have relevance for other relationship-based programming settings.

#### *Study Limitations*

There were several limitations inherent in this study. First, children were at camp for a short period of time. This may have limited camp impacts. Second, the size of the camp population was small, and only a small sample of campers was interviewed. Third, the study was limited to children attending only one camp. Fourth, the study would have benefited from utilizing data from focus groups with social workers and CITs, and camper and parent post-camp interviews to strengthen understanding of camp impacts and the carryover of camp impacts back to the campers' everyday lives.

#### *Future Research*

The demand for evidence to support the efficacy of camp programs is increasingly needed. Research studies must continue to be conducted to document the benefits and efficacy of camps if agencies seeking financial support from grants, donors and foundations are going to successfully raise funds for their endeavors.



Recommendations for research include the consideration of alternate methodologies. For example, use of quantitative approaches for testing the suggested modification of House's framework, would provide additional evidence that could be used to strengthen approaches to designing intentionality in camp practices.. Future research on social support impact at specialty camps is encouraged and to what extent parents should be involved at some point in the siblings camping experience. Recognizing that the development of and implications for social support can differ by camp mission, it also would be beneficial to study social comparison as a mechanism of social support in different camp types, especially specialty camps.

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## **APPENDIX A**

### **Qualitative Questions for Campers at Camp**

I came to camp because

Did you like being at camp?

What did you learn by being at camp?

Tell me about your brother or sister who has cancer

How does their having cancer make you feel?

How did camp help you with your feelings?

My favorite part of camp was

My least favorite part of camp was

If I could change one thing about camp, it would be

Did you make friends at camp? If yes, tell me about them

### **Qualitative Questions for Children after One Month**

What did you learn by being at camp?

Now that you've been home for a month, tell me about your camp experiences

Did going to camp make any difference in your life?

Did camp help you with your feelings about your sibling?

Now that you are thinking about, what part of camp did you like best, least?

### **Qualitative Questions for CITs**

How many years were you a camper at this camp?

What are your best memories of being a camper?

How did being at camp make a difference in your life?

What or who do you credit as your top sources of support?

Why did you choose to be a CIT?

What did you get out of being a CIT this summer?

What difference did your presence make in the lives of the campers?

How is the camp different than it was when you were a camper?

Are there things being done at camp that you would have liked to have included when you were a camper?

What are the best things about this camp?

Are there things you would recommend to improve camp?

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